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Second Session  
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Deuxième session de la  
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## SENATE OF CANADA

## SÉNAT DU CANADA

*Standing Senate Committee on Social Affairs,  
Science and Technology*

*Comité sénatorial permanent des affaires sociales, des  
sciences et de la technologie*

*Proceedings of the Subcommittee to*

*Délibérations du sous-comité de*

# Update “Of Life and Death”

# Mise à jour de «De la vie et de la mort»

*Chair:*

The Honourable SHARON CARSTAIRS

*Présidente:*

L'honorable SHARON CARSTAIRS

Tuesday, November 30, 1999  
Tuesday, February 8, 2000  
Monday, February 14, 2000

Le mardi 30 novembre 1999  
Le mardi 8 février 2000  
Le lundi 14 février 2000

Issue No. 1

Fascicule n° 1

### Organization meeting Future business and first meeting on:

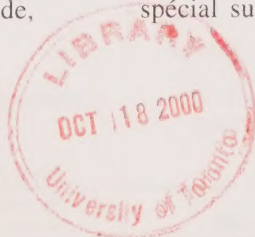
Examination of the developments since the tabling in  
June 1995 of the final report of the Special Senate  
Committee on Euthanasia and Assisted Suicide,  
entitled “Of Life and Death”

### Séance d'organisation Travaux futurs et première réunion concernant:

L'étude des faits nouveaux survenus depuis le dépôt,  
en juin 1995, du rapport final du comité sénatorial  
spécial sur l'euthanasie et l'aide au suicide intitulé  
«De la vie et de la mort»

WITNESSES:  
(See back cover)

TÉMOINS:  
(Voir à l'endos)





## THE SUBCOMMITTEE TO UPDATE “OF LIFE AND DEATH”

The Honourable Sharon Carstairs, *Chair*

The Honourable Gérard-A. Beaudoin, *Deputy Chair*

and

The Honourable Senators:

\*Boudreau, P.C.  
(or Hays)  
Corbin  
Keon

\*Lynch-Staunton  
(or Kinsella)  
Pépin

\* *Ex Officio Members*

(Quorum 3)

*Changes in membership of the committee:*

Pursuant to rule 85(4), membership of the committee was amended as follows:

The name of the Honourable Senator Corbin substituted for that of the Honourable Senator Kirby (*February 14, 2000*).

The name of the Honourable Senator Beaudoin substituted for that of the Honourable Senator Robertson (*February 14, 2000*).

The name of the Honourable Senator Kirby substituted for that of the Honourable Senator Robichaud, P.C. (*February 8, 2000*).

The name of the Honourable Senator Robertson substituted for that of the Honourable Senator Beaudoin (*February 8, 2000*).

The name of the Honourable Senator Beaudoin substituted for that of the Honourable Senator Robertson (*February 7, 2000*).

The name of the Honourable Senator Robichaud, P.C. substituted for that of the Honourable Senator Kirby (*February 7, 2000*).

The name of the Honourable Senator Robertson substituted for that of the Honourable Senator Beaudoin (*November 30, 1999*).

## LE SOUS-COMITÉ DE MISE À JOUR DE «DE LA VIE ET DE LA MORT»

*Présidente:* L'honorable Sharon Carstairs

*Vice-président:* L'honorable Gérard-A. Beaudoin

et

Les honorables sénateurs:

\*Boudreau, c.p.  
(ou Hays)  
Corbin  
Keon

\*Lynch-Staunton  
(ou Kinsella)  
Pépin

\* *Membres d'office*

(Quorum 3)

*Modifications de la composition du comité:*

Conformément à l'article 85(4) du Règlement, la liste des membres du comité est modifiée, ainsi qu'il suit:

Le nom de l'honorable sénateur Corbin est substitué à celui de l'honorable sénateur Kirby (*le 14 février 2000*).

Le nom de l'honorable sénateur Beaudoin est substitué à celui de l'honorable sénateur Robertson (*le 14 février 2000*).

Le nom de l'honorable sénateur Kirby est substitué à celui de l'honorable sénateur Robichaud, c.p. (*le 8 février 2000*).

Le nom de l'honorable sénateur Robertson est substitué à celui de l'honorable sénateur Beaudoin (*le 8 février 2000*).

Le nom de l'honorable sénateur Beaudoin est substitué à celui de l'honorable sénateur Robertson (*le 7 février 2000*).

Le nom de l'honorable sénateur Robichaud, c.p. est substitué à celui de l'honorable sénateur Kirby (*le 7 février 2000*).

Le nom de l'honorable sénateur Robertson est substitué à celui de l'honorable sénateur Beaudoin (*le 30 novembre 1999*).



## ORDERS OF REFERENCE

Extract from the *Journals of the Senate* of Thursday, November 25, 1999:

Resuming debate on the motion of the Honourable Senator Carstairs, seconded by the Honourable Senator Mercier:

That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report upon developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled: *Of Life and Death*. In particular, the Committee shall be authorized to examine:

1. The progress on the implementation of the unanimous recommendations made in the report;
2. Developments in Canada respecting the issues dealt with in the report;
3. Developments in foreign jurisdictions respecting the issues dealt with in the report; and

That the Committee submit its final report no later than June 6, 2000.

After debate,

The question being put on the motion, it was adopted.

*Le greffier du Sénat,*

Paul C. Bélisle

*Clerk of the Senate*

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Extract from the *Minutes of Proceedings from the Standing Senate Committee on Social Affairs, Science and Technology* of Monday, November 29, 1999:

It was moved by Senator Carstairs — That a Subcommittee to Update “Of Life and Death” be established, comprising five members, including the Honourable Senators: Carstairs, Kirby, Pépin, Beaudoin and Keon;

That the Order of Reference adopted by the Senate on Thursday, November 25, 1999:

That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report upon developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled: *Of Life and Death*. In particular, the Committee shall be authorized to examine:

1. The progress on the implementation of the unanimous recommendations made in the report;

## ORDRES DE RENVOI

Extrait des *Journaux du Sénat* du jeudi 25 novembre 1999:

Reprise du débat sur la motion de l'honorable sénateur Carstairs, appuyée par l'honorable sénateur Mercier,

Que le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie soit autorisé à examiner pour en faire rapport les faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du Comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé *De la vie et de la mort*. Plus particulièrement, que le Comité soit autorisé à examiner:

1. La mesure dans laquelle ont été mises en oeuvre les recommandations unanimes présentes dans le rapport;
2. L'évolution au Canada des différentes questions étudiées dans le rapport;
3. L'évolution à l'étranger des différentes questions étudiées dans le rapport;

Que le Comité présente son rapport final au plus tard le 6 juin 2000.

Après débat,

La motion, mise aux voix, est adoptée.

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Extrait du *Procès-verbal du comité sénatorial permanent des affaires sociales, des sciences et de la technologie*, du lundi 29 novembre 1999:

Le sénateur Carstairs propose — Que soit formé un sous-comité chargé de mettre à jour le rapport «De la vie et de la mort» et qu'il se compose de cinq membres, y compris des honorables sénateurs Carstairs, Kirby, Pépin, Beaudoin et Keon;

Que l'ordre de renvoi adopté par le Sénat le jeudi 25 novembre 1999, soit

Que le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie soit autorisé à examiner pour en faire rapport les faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du Comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé: *De la vie et de la mort*. Plus particulièrement, que le comité soit autorisé à examiner:

1. La mesure dans laquelle ont été mises en oeuvre les recommandations unanimes présentes dans le rapport;



2. Developments in Canada respecting the issues dealt with in the report;

3. Developments in foreign jurisdictions respecting the issues dealt with in the report; and

That the Committee submit its final report no later than June 6, 2000;

be referred to the Subcommittee.

That the Subcommittee be authorized to send for persons, papers and records, whenever required, and to print from day to day such papers and evidence as may be ordered by it;

That, pursuant to Section 32 of the Financial Administration Act, the Committee's authority to commit funds be conferred on the Subcommittee;

That, pursuant to Section 34 of the Financial Administration Act and Guideline 3:05 of Appendix II of the *Rules of the Senate*, the Committee's authority for certifying accounts payable be conferred on the Subcommittee; and

That the Committee's power to permit coverage by electronic media of meetings be conferred on the Subcommittee.

The question being put on the motion, it was agreed.

2. L'évolution au Canada des différentes questions étudiées dans le rapport;

3. L'évolution à l'étranger des différentes questions étudiées dans le rapport;

Que le comité présente son rapport final au plus tard le 6 juin 2000,

soit renvoyé au sous-comité;

Que le sous-comité soit autorisé à inviter les témoins qu'il juge nécessaire et à exiger la production de documents et de dossiers au besoin, de même qu'à les faire publier au jour le jour;

Que, conformément à l'article 32 de la Loi sur la gestion des finances publiques, le pouvoir du comité d'engager des fonds soit conféré au sous-comité;

Que, conformément à l'article 34 de la Loi sur la gestion des finances publiques et la directive 3:05 de l'annexe II du *Règlement du Sénat*, le pouvoir qu'a le comité d'attester les comptes à payer soit conféré au sous-comité; et

Que le pouvoir qu'a le comité d'autoriser la diffusion des réunions sur support électronique soit conféré au sous-comité.

La motion, mise aux voix, est adoptée.

*Le greffier du comité,*

Catherine Piccinin

*Clerk of the Committee*

**MINUTES OF PROCEEDINGS**

OTTAWA, Tuesday, November 30, 1999

(1)

[English]

The Subcommittee to update "Of Life and Death" met this day in room 172-E, Centre Block, at 11:04 a.m., for the purpose of organization.

*Members of the subcommittee present:* The Honourable Senators Beaudoin, Carstairs, Kirby and Pépin (4).

*Other senator present:* The Honourable Senator Corbin (1).

Pursuant to rule 88, the Clerk of the Subcommittee presided over the election of the Chair.

The Honourable Senator Kirby moved — That the Honourable Senator Carstairs be Chair of this Subcommittee.

The question being put on the motion, it was agreed.

The Honourable Senator Carstairs took the Chair of the Subcommittee and made some opening remarks.

The Honourable Senator Kirby moved — That the Honourable Senator Beaudoin be Deputy Chair of this Subcommittee.

The question being put on the motion, it was agreed.

The Honourable Senator Pépin moved — That the subcommittee print 300 copies of its Proceedings and That the Chair be authorized to adjust this number to meet demand.

The question being put on the motion, it was agreed.

The Honourable Senator Pépin moved — That, pursuant to rule 89, the Chair be authorized to hold meetings, to receive and authorize the printing of the evidence when a quorum is not present, provided That a representative of the government and a representative from the opposition are present.

The question being put on the motion, it was agreed.

The Honourable Senator Kirby moved — That the subcommittee ask the Library of Parliament to assign research officers to the subcommittee, and;

That the Chair, on behalf of the Subcommittee, direct the research staff in the preparation of studies, analyses, summaries and draft reports.

After debate, the question being put on the motion, it was agreed.

The Honourable Senator Kirby moved — That, pursuant to section 32 of the Financial Administration Act, authority to commit funds be conferred on the Chair or in the Chair's absence, the Deputy Chair; and

That, pursuant to section 34 of the Financial Administration Act, and Guideline 3:05 of Appendix II of the *Rules of the Senate*, authority for certifying accounts payable by the Subcommittee be conferred individually on the Chair, the Deputy Chair, and the Clerk of the Subcommittee.

The question being put on the motion, it was agreed.

**PROCÈS-VERBAUX**

OTTAWA, le mardi 30 novembre 1999

(1)

[Traduction]

Le sous-comité de mise à jour de «De la vie et de la mort» se réunit aujourd'hui à 11 h 04, dans la pièce 172-E de l'édifice du Centre, pour organiser ses travaux.

*Membres du sous-comité présents:* Les honorables sénateurs Beaudoin, Carstairs, Kirby et Pépin (4).

*Autre sénateur présent:* L'honorable sénateur Corbin (1).

Conformément à l'article 88 du Règlement du Sénat, le greffier du comité préside à l'élection à la présidence.

L'honorable sénateur Kirby propose — Que l'honorable sénateur Carstairs soit présidente du sous-comité.

La question, mise aux voix, est adoptée.

L'honorable sénateur Carstairs occupe le fauteuil du sous-comité et fait certaines remarques.

L'honorable sénateur Kirby propose — Que l'honorable sénateur Beaudoin soit vice-président de ce sous-comité.

La question, mise aux voix, est adoptée.

L'honorable sénateur Pépin propose — Que le sous-comité fasse imprimer 300 exemplaires de ses délibérations et que la présidence soit autorisée à ajuster cette quantité en fonction des besoins.

La question, mise aux voix, est adoptée.

L'honorable sénateur Pépin propose — Que, conformément à l'article 89 du Règlement, la présidence soit autorisée à tenir des réunions pour entendre des témoignages et à en permettre la publication en l'absence de quorum, pourvu qu'un représentant du gouvernement et un représentant de l'opposition soient présents.

La question, mise aux voix, est adoptée.

L'honorable sénateur Kirby propose — Que le sous-comité demande à la Bibliothèque du Parlement d'affecter des attachés de recherche auprès du sous-comité, et

Que la présidente, au nom du sous-comité, dirige le personnel de recherche dans la préparation d'études, d'analyses, de résumés et de projets de rapports.

Après discussion, la question, mise aux voix, est adoptée.

L'honorable sénateur Kirby propose — Que conformément à l'article 32 de la Loi sur la gestion des finances publiques, l'autorisation d'empêcher les fonds du sous-comité soit conférée à la présidence, ou en son absence, la vice-présidence; et

Que, conformément à l'article 34 de la Loi sur la gestion des finances publiques et à la directive 3:05 de l'annexe II du *Règlement du Sénat*, l'autorisation d'approuver les comptes à payer au nom du sous-comité soit conférée individuellement à la présidence, à la vice-présidence et au greffier du sous-comité.

La question, mise aux voix, est adoptée.



The Honourable Senator Beaudoin moved — That, pursuant to the Senate guidelines for witnesses expenses, the Subcommittee may reimburse reasonable travelling and living expenses for one witness from any one organization and payment will take place upon application, but That the Chair be authorized to approve expenses for a second witness should there be exceptional circumstances.

The subcommittee proceeded to the consideration of the subcommittee's meeting time.

After discussion, it was agreed — That the regular time slot for the subcommittee be Tuesdays, from 9:00 to 11:00 a.m.

The committee proceeded to the consideration of a draft budget.

It was agreed — That the following budget be submitted to the Standing Senate Committee on Social Affairs, Science and Technology for approval and submission to Internal Economy, Budgets and Administration:

Professional and Other Services	\$1,850
Transportation & Communication	\$4,790
Other Expenditures	<u>\$1,250</u>
<b>Total</b>	<b>\$7,890</b>

The question being put on the motion, it was agreed.

The subcommittee proceeded to discuss the workplan.

The Honourable Senator Kirby moved — That staff be directed to write to the provinces with respect to updating information in those provinces with respect to the unanimous recommendations found in the report.

The question being put on the motion, it was agreed.

It was agreed — That the staff be authorized to identify, contact and schedule witnesses with respect to the issues in the unanimous recommendations of the report and the progress of those unanimous recommendations in order to begin hearings in February 2000.

It was agreed — That the Minister of Health and the Minister of Justice be invited to appear before the subcommittee and That a letter be sent to each outlining the matters to which the Subcommittee would like them to speak and That members be sent copies of those letters.

At 11:29 a.m., the subcommittee adjourned to the call of the Chair.

ATTEST:

OTTAWA, Tuesday, February 8, 2000

(2)

[English]

The Subcommittee to update "Of Life and Death" met this day *in camera* in room 157 East Block, at 10:07 a.m., the Honourable Sharon Carstairs, Chair, presiding.

L'honorable sénateur Beaudoin propose — Que, conformément aux lignes directrices du Sénat régissant les frais de déplacements des témoins, le sous-comité puisse rembourser des dépenses raisonnables de voyage et d'hébergement à un témoin d'un même organisme, après qu'une demande de remboursement a été présentée, mais que la présidence soit autorisée à permettre le remboursement des dépenses pour un deuxième témoin s'il y a des circonstances exceptionnelles.

Le comité se penche sur l'horaire des séances du sous-comité.

Après discussion, il est convenu que l'horaire des séances régulières du sous-comité soit le mardi de 9 heures à 11 heures.

Le comité se penche sur une ébauche de budget.

Il est convenu — Que le budget suivant soit soumis au comité permanent des affaires sociales, des sciences et de la technologie aux fins d'approbation de présentation au comité de la régie interne, des budgets et de l'administration:

Services professionnels et autres	1 850 \$
Transports et communications	4 790
Autres dépenses	<u>1 250</u>
<b>Total</b>	<b>7 890 \$</b>

La question, mise aux voix, est adoptée.

Le comité discute du plan de travail.

L'honorable sénateur Kirby propose — Que l'on demande au personnel de communiquer avec les autorités provinciales afin d'obtenir une mise à jour de l'information concernant leur province au sujet des recommandations unanimes du rapport.

La question, mise aux voix, est adoptée.

Il est convenu — Que le personnel soit autorisé à dresser une liste et à communiquer avec des témoins au sujet des recommandations unanimes et des progrès réalisés quant à leur mise en oeuvre afin d'entreprendre les audiences en février 2000.

Il est convenu — Que le ministre de la Santé et le ministre de la Justice soient invités à comparaître devant le sous-comité et que l'on communique avec chacun d'entre eux afin de leur préciser les questions que le sous-comité aimerait qu'ils abordent et que des copies de ces lettres soient remises aux membres du sous-comité.

À 11 h 29, le sous-comité suspend ses travaux jusqu'à nouvelle convocation de la présidence.

ATTESTÉ:

OTTAWA, le mardi 8 février 2000

(2)

[Traduction]

Le sous-comité de mise à jour de «De la vie et de la mort» se réunit aujourd'hui à huis clos, à 10 h 07, dans la salle 157 de l'édifice de l'Est, sous la présidence de l'honorable Sharon Carstairs (*présidente*).

*Members of the subcommittee present:* The Honourable Senators Beaudoin, Carstairs, and Robichaud, P.C. (3).

*Other senators present:* The Honourable Senators Corbin and Roche (2).

The subcommittee proceeded to consider future business.

The Chair reviewed the witnesses and workplan.

It was agreed — That, when possible, Monday meetings would start at 2:00 p.m.

The schedule and witnesses were approved, but it was agreed — That changes could be made depending on the availability of witnesses.

The subcommittee reviewed and approved the format of the briefing notes prepared by the Library of Parliament.

It was agreed — That, in addition to the witnesses approved, the subcommittee invite the Catholic Health Association and Professors Marguerite Somerville and Arthur Shafer to appear before the subcommittee.

The subcommittee discussed videotaping for television coverage, and it was agreed — That CPAC be asked to broadcast the hearings gavel to gavel. It was also agreed That a disclaimer be included in the credits confirming — That the meeting presently broadcast is part of a series of hearings.

The subcommittee reviewed the draft press release and, subject to a minor change, agreed to release it on February 14.

It was agreed — That all decisions taken by the subcommittee in this meeting be included in the next printed Minutes of Proceedings of the Committee.

At 10:41 a.m., the subcommittee adjourned to the call of the Chair.

ATTEST:

*La greffière du sous-comité,*

Heather Lank

*Clerk of the Subcommittee*

OTTAWA, Monday, February 14, 2000  
(3)

[English]

The Subcommittee to update "Of Life and Death" met this day in room 257, East Block, at 2:01 p.m., the Honourable Sharon Carstairs, Chair, presiding.

*Members of the subcommittee present:* The Honourable Senators Beaudoin, Carstairs, Corbin and Pélipin (4).

*Other senator present:* The Honourable Senator Roche (1).

*Membres du sous-comité présents:* Les honorables sénateurs Beaudoin, Carstairs et Robichaud, c.p. (3)

*Autres sénateurs présents:* Les honorables sénateurs Corbin et Roche (2).

Le sous-comité examine ses travaux futurs.

La présidente examine la liste des témoins et le plan de travail.

Il est convenu — Que, lorsque c'est possible, les réunions du lundi devraient débiter à 14 heures.

L'échéancier et la liste des témoins sont approuvés, mais il est entendu — Que d'éventuels changements pourraient être apportés selon la disponibilité des témoins.

Le sous-comité examine et approuve la présentation des notes d'information préparées par la Bibliothèque du Parlement.

Il est entendu — Qu'en plus des témoins de la liste approuvée, le sous-comité invitera la Catholic Health Association de même que les professeurs Marguerite Somerville et Arthur Shafer à venir témoigner.

Le sous-comité délibère de la possibilité d'enregistrer sur bande magnétoscopique ses audiences de manière à pouvoir les télédiffuser, et il est convenu — Que la CPAC sera priée de diffuser les audiences du début jusqu'à la fin. Il est également convenu de faire ajouter dans le générique un avertissement que la séance en cours de diffusion fait partie d'une série.

Le sous-comité examine l'ébauche d'un communiqué de presse et, sous réserve d'un léger changement, accepte de le diffuser le 14 février.

Il est convenu — Que toutes les décisions prises par le sous-comité durant la séance seront incluses dans le prochain procès-verbal imprimé du comité.

À 10 h 41, le comité s'ajourne jusqu'à nouvelle convocation de la présidence.

ATTESTÉ:

OTTAWA, le lundi 14 février 2000  
(3)

[Traduction]

Le sous-comité de mise à jour de «De la vie et de la mort» se réunit aujourd'hui, à 14 h 01, dans la salle 257 de l'édifice de l'Est, sous la présidence de l'honorable Sharon Carstairs (présidente).

*Membres du comité présents:* Les honorables sénateurs Beaudoin, Carstairs, Corbin et Pélipin (4).

*Autre sénateur présent:* L'honorable sénateur Roche (1).



*In attendance:* Mollie Dunsmuir and Nancy Miller-Chénier, Research Officers, Research Branch, Library of Parliament.

Pursuant to its order of reference adopted in the Standing Senate Committee on Social Affairs, Science and Technology on Monday, November 29, 1999, the subcommittee commenced its examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death".

*WITNESSES:*

Professor Jocelyn Downie, Health Law Institute, Dalhousie University.

Professor Barney Sneiderman, Faculty of Law, University of Manitoba.

The Chair made an opening statement.

Professor Downie made a statement.

Professor Sneiderman made a statement.

The witnesses answered questions.

At 2:49 p.m., the Honourable Senator Pépin took the Chair.

At 2:50 p.m., the Honourable Senator Carstairs resumed the Chair.

At 4:09 p.m., the subcommittee adjourned to the call of the Chair.

*ATTEST:*

*Également présentes:* Mollie Dunsmuir et Nancy Miller-Chénier, attachées de recherche, Direction de la recherche parlementaire, Bibliothèque du Parlement.

En conformité avec l'ordre de renvoi adopté par le comité sénatorial permanent des affaires sociales, des sciences et de la technologie le lundi 29 novembre 1999, le sous-comité entame son examen des faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé «De la vie et de la mort».

*TÉMOINS:*

Jocelyn Downie, professeure, Health Law Institute, Université Dalhousie.

Barney Sneiderman, professeur, Faculté de droit, Université du Manitoba.

La présidente prononce un mot d'ouverture.

Mme Downie fait un exposé.

M. Sneiderman fait un exposé.

Les témoins répondent aux questions.

À 14 h 49, l'honorable sénateur Pépin prend le fauteuil.

À 14 h 50, l'honorable sénateur Carstairs reprend le fauteuil.

À 16 h 09, le comité s'ajourne jusqu'à nouvelle convocation de la présidence.

*ATTESTÉ:*

*La greffière suppléante du sous-comité,*

Catherine Piccinin

*Acting Clerk of the Subcommittee*

**EVIDENCE**

OTTAWA, Tuesday, November 30, 1999

The Subcommittee to Update “Of Life and Death” of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 11:00 a.m. to organize the activities of the committee.

**Ms Heather Lank, Clerk of the Committee:** Honourable senators, we have a quorum. As clerk of your subcommittee, it is my duty to preside over the election of the chair. I am ready to receive motions.

[English]

**Senator Kirby:** I move that Senator Carstairs be the Chair.

**Ms Lank:** Are there any other motions? There being none, is it your pleasure, honourable senators, to adopt the motion?

**Hon. Senators:** Agreed.

**Ms Lank:** The motion is carried. I invite Senator Carstairs to take the chair.

**Senator Sharon Carstairs** (*Chairman*) in the Chair.

**The Chairman:** Honourable senators, thank you for bestowing upon me the chairmanship of this committee.

You have some documentation in front of you. You have a copy of the report “Of Life and Death”. You also have a background note to update “Of Life and Death” prepared by Mollie Dunsmuir. Those of you who were on the committee with me will remember that she was our researcher at that time. She has maintained her interest in this file and did an update in 1998. I asked her to do a further update this year. This is literally hot off the press, dated November 25, 1999. The background information will update you on a number of situations that have occurred since the report was originally prepared. You also have in front of you a budget for the fiscal year ending March 31, 2000 and another one for the fiscal year ending June 6, 2000.

Let us begin with a number of motions we need to put into place in order to ensure that the subcommittee functions properly.

Senator Beaudoin, are you prepared to be the deputy chair of this committee?

**Senator Beaudoin:** If it is necessary.

**Senator Kirby:** I move that motion.

**The Chairman:** Is it agreed, honourable senators?

**Hon. Senators:** Agreed.

**The Chairman:** Carried.

**Senator Pépin:** I move

That the Subcommittee print 300 copies of its Proceedings and that the Chair be authorized to adjust this number to meet demand.

**The Chairman:** Is it your pleasure, honourable senators, to adopt the motion?

**TÉMOIGNAGES**

OTTAWA, le mardi 30 novembre 1999

Le sous-comité de mise à jour de «De la vie et de la mort» du comité sénatorial permanent des affaires sociales, des sciences et de la technologie se réunit aujourd’hui à 11 heures pour organiser ses activités.

**Mme Heather Lank, greffière du comité:** Honorables sénateurs, nous avons quorum. En tant que greffière de votre sous-comité, il est de mon devoir de présider à l’élection de la présidence. Je suis prête à accueillir des motions.

[Traduction]

**Le sénateur Kirby:** Je propose que le sénateur Carstairs assume la présidence.

**Mme Lank:** Y a-t-il d’autres motions? Comme il n’y en a pas d’autres, êtes-vous d’accord, honorables sénateurs, pour adopter la motion?

**Des voix:** D’accord.

**Mme Lank:** La motion est adoptée. J’invite le sénateur Carstairs à occuper le fauteuil.

**Le sénateur Sharon Carstairs** (*présidente*) occupe le fauteuil.

**La présidente:** Honorables sénateurs, je vous remercie de m’avoir confié la présidence du comité.

Vous avez devant vous des documents: un exemplaire du rapport «De la vie et de la mort» ainsi qu’une note d’information préparée par Mollie Dunsmuir au sujet de la mise à jour de «De la vie et de la mort». Ceux d’entre vous qui siégez au comité avec moi se souviendront qu’elle était notre attachée de recherche à l’époque. Elle a continué de s’intéresser à ce dossier et a effectué une mise à jour en 1998. Je lui ai demandé d’en faire une autre cette année. Cette dernière version vient tout juste d’être imprimée, le 25 novembre dernier. Le document d’information fait le point sur un certain nombre de situations qui sont survenues depuis la rédaction du rapport original. Vous avez également en main une ébauche de budget pour l’exercice financier se terminant le 31 mars 2000 et un autre pour l’exercice financier se terminant le 6 juin 2000.

Commençons par un certain nombre de motions qu’il nous faut adopter pour assurer le bon fonctionnement du sous-comité.

Sénateur Beaudoin, êtes-vous disposé à être vice-président du comité?

**Le sénateur Beaudoin:** Si c’est nécessaire.

**Le sénateur Kirby:** Je propose cette motion.

**La présidente:** Êtes-vous d’accord, honorables sénateurs?

**Des voix:** D’accord.

**La présidente:** Adoptée.

**Le sénateur Pépin:** Je propose

Que le sous-comité fasse imprimer 300 exemplaires de ses délibérations et que la présidence soit autorisée à ajuster cette quantité en fonction des besoins.

**La présidente:** Honorables sénateurs, êtes-vous d’accord pour adopter la motion?



**Hon. Senators:** Agreed.

**The Chairman:** Carried.

**Senator Pépin:** I move:

That, pursuant to Rule 89, the Chair be authorized to hold meetings, to receive and authorize the printing of the evidence when a quorum is not present, provided that a representative of the government and a representative from the opposition are present.

**The Chairman:** Is it your pleasure, honourable senators, to adopt the motion?

**Hon. Senators:** Agreed.

**The Chairman:** I would entertain the following motion:

That the Subcommittee ask the Library of Parliament to assign research officers to the Subcommittee and that the Chair, on behalf of the Subcommittee, direct the research staff in preparation of studies, analyses, summaries and draft reports.

**Senator Kirby:** I so move.

**Senator Corbin:** I am not a member of the subcommittee, but you have invited me to attend. You are going fairly fast on this.

**The Chairman:** These are all normal motions.

**Senator Corbin:** I do not accept anything as normal anymore. Would you repeat the text of that motion?

**The Chairman:** The motion reads:

That the Subcommittee ask the Library of Parliament to assign research officers to the Subcommittee and that the Chair, on behalf of the Subcommittee, direct the research staff in the preparation of studies, analyses, summaries and draft reports.

**Senator Beaudoin:** I do not have any problem with the first part of that. I have a problem with the second part because this is a committee, not a one-person committee.

**The Chairman:** Remember that the chair can act only on behalf of the subcommittee.

**Senator Kirby:** The researcher needs someone to report to, and they report to the chair. The chair can direct the research staff only on behalf of the subcommittee.

**Senator Beaudoin:** Once the subcommittee has made a decision.

**The Chairman:** Exactly.

**Senator Corbin:** That is to be interpreted along the lines suggested by the subcommittee.

**The Chairman:** Exactly.

**Senator Corbin:** In other words, you cannot take a totally different approach from the committee members or diverge considerably from the consensus developed.

**Des voix:** D'accord.

**La présidente:** Adoptée.

**Le sénateur Pépin:** Je propose:

Que, conformément à l'article 89 du Règlement, la présidence soit autorisée à tenir des réunions pour entendre des témoignages et à en permettre la publication en l'absence de quorum, pourvu qu'un représentant du gouvernement et un représentant de l'opposition soient présents.

**La présidente:** Honorables sénateurs, êtes-vous d'accord pour adopter la motion?

**Des voix:** D'accord.

**La présidente:** Je suis prête à accueillir la motion suivante:

Que le sous-comité demande à la Bibliothèque du Parlement d'affecter des attachés de recherche auprès du sous-comité et que la présidence, au nom du sous-comité, dirige le personnel de recherche dans la préparation d'études, d'analyses, de résumés et de projets de rapport.

**Le sénateur Kirby:** J'en fais la proposition.

**Le sénateur Corbin:** Je ne suis pas membre du sous-comité, mais vous m'avez invité à assister à la séance. Vous allez plutôt vite.

**La présidente:** Ce sont toutes des motions de routine.

**Le sénateur Corbin:** À mon avis, il n'y a plus rien de routinier. Pouvez-vous répéter le texte de cette motion?

**La présidente:** La motion se lit ainsi:

Que le sous-comité demande à la Bibliothèque du Parlement d'affecter des attachés de recherche auprès du sous-comité et que la présidence, au nom du sous-comité, dirige le personnel de recherche dans la préparation d'études, d'analyses, de résumés et de projets de rapport.

**Le sénateur Beaudoin:** La première partie de la motion ne me cause aucun problème, mais ce n'est pas le cas de la deuxième. En effet, il s'agit d'un comité, et non d'un comité composé d'une seule personne.

**La présidente:** Rappelez-vous que la présidence ne peut agir qu'au nom du sous-comité.

**Le sénateur Kirby:** L'attaché de recherche doit faire rapport à quelqu'un, et ce quelqu'un c'est la présidence. La présidence peut donner des ordres à l'équipe de recherche uniquement au nom du sous-comité.

**Le sénateur Beaudoin:** Une fois que le sous-comité a pris une décision.

**La présidente:** Exactement.

**Le sénateur Corbin:** Cela doit être interprété selon l'orientation suggérée par le sous-comité.

**La présidente:** Tout à fait.

**Le sénateur Corbin:** Autrement dit, vous ne pouvez adopter une approche totalement différente des membres du comité ou diverger sensiblement du consensus établi.

**The Chairman:** Absolutely. It must be on behalf of the subcommittee. Is it your pleasure to adopt the motion?

**Hon. Senators:** Agreed.

**The Chairman:** Carried. Would someone move:

That, pursuant to section 32 of the Financial Administration Act, authority to commit funds be conferred on the Chair or, in the Chair's absence, the Deputy Chair; and

That, pursuant to section 34 of the Financial Administration Act, and guideline 3:05 of Appendix II of the *Rules of the Senate*, authority for certifying accounts payable by the Subcommittee be conferred individually on the Chair, the Deputy Chair and the Clerk of the Subcommittee.

**Senator Kirby:** I so move.

**The Chairman:** Is it your pleasure, honourable senators, to adopt the motion?

**Hon. Senators:** Agreed.

**The Chairman:** Carried. I will now entertain the following motion:

That, pursuant to the Senate guidelines for witnesses' expenses, the Subcommittee reimburse reasonable travelling and living expenses for one witness from any one organization and payment will take place upon application, but that the Chair be authorized to approve expenses for a second witness should there be exceptional circumstances.

That is the rule we used in the Standing Senate Committee on Legal and Constitutional Affairs. However, if there were exceptional circumstances, for example, if a handicapped person needed an assistant in order to come and appear before us, we would also pay for that person.

**Senator Corbin:** Is it your intention to call many outside witnesses?

**The Chairman:** That will be up to the committee, but I hope that we can make some determination today of the kinds of witnesses from whom we would want to hear.

**Senator Beaudoin:** I have a problem here in that I have so many committees to attend that I do not have the time to travel. If the witnesses are coming here, I agree. However, if we must travel to them, then I have a problem.

**The Chairman:** Senator Beaudoin, you will see from your budget that there is no travelling at all. All meetings will take place here.

**Senator Beaudoin:** The best example is given by the Standing Senate Committee on Legal and Constitutional Affairs, which is a very good committee and does not cost anything.

**La présidente:** Absolument. Je dois agir au nom du sous-comité. Honorables sénateurs, êtes-vous d'accord pour adopter la motion?

**Des voix:** D'accord.

**La présidente:** D'adoptée. Quelqu'un pourrait-il proposer:

Que, conformément à l'article 32 de la Loi sur la gestion des finances publiques, l'autorisation d'engager les fonds du sous-comité soit conférée à la présidence, en son absence, la vice-présidence; et

Que, conformément à l'article 34 de la Loi sur la gestion des finances publiques et à la directive 3:05 de l'annexe II du *Règlement du Sénat*, l'autorisation d'approuver les comptes à payer au nom du sous-comité soit conférée individuellement à la présidence, la vice-présidence et au greffier du sous-comité.

**Le sénateur Kirby:** J'en fais la proposition.

**La présidente:** Honorables sénateurs, êtes-vous d'accord pour adopter la motion?

**Des voix:** D'accord.

**La présidente:** Adoptée. Je vais maintenant accueillir la motion suivante:

Que, conformément aux lignes directrices du Sénat gouvernant les frais de déplacement des témoins, le sous-comité peut rembourser des dépenses raisonnables de voyage et d'hébergement à un témoin d'un même organisme, après qu'une demande de remboursement ait été présentée, mais que la présidence soit autorisée à permettre le remboursement de dépenses pour un deuxième témoin en cas de circonstances exceptionnelles.

C'est la règle que nous utilisons au comité permanent des affaires juridiques et constitutionnelles. Ainsi, en cas de circonstances exceptionnelles, par exemple si une personne handicapée avait besoin d'être accompagnée pour venir comparaître devant nous, nous paierions aussi les dépenses de cette personne.

**Le sénateur Corbin:** Avez-vous l'intention de convoquer un grand nombre de témoins de l'extérieur?

**La présidente:** La décision appartient au comité, mais j'espère que nous pourrions aujourd'hui décider quel témoins nous voudrions entendre.

**Le sénateur Beaudoin:** J'ai un problème, en ce sens que je siège à tellement de comités que je n'ai pas le temps de voyager. Si les témoins viennent ici, je n'ai pas d'objections. Cependant, si nous devons nous déplacer pour les entendre, à ce moment-là, j'ai un problème.

**La présidente:** Sénateur Beaudoin, si vous consultez notre budget, vous verrez qu'aucun déplacement n'est prévu. Toutes les séances auront lieu ici.

**Le sénateur Beaudoin:** Le meilleur exemple est celui du comité permanent des affaires juridiques et constitutionnelles. C'est un très bon comité qui ne coûte pratiquement rien.



**The Chairman:** This is the travelling and living expenses of witnesses, not the travelling and living expenses of senators.

**Senator Beaudoin:** That is fine. I so move.

**The Chairman:** Is it your pleasure, honourable senators, to adopt the motion?

**Hon. Senators:** Agreed.

**The Chairman:** Carried.

With regard to the time slot for regular meetings of this subcommittee, the Social Affairs Committee meets at 3:30 p.m. on Wednesdays and at 11:30 a.m. on Thursdays. That provides some conflict for you because of the Standing Senate Committee on Legal and Constitutional Affairs. I suggest that we limit the number of meetings we have to begin with, but that we try to set Monday afternoons with plenty of advance warning — that is, if that is agreeable to people.

**Senator Beaudoin:** Monday afternoons?

**Senator Kirby:** I do not like Monday afternoons. That messes up the one day of the week that I do not have to be here. What about Tuesday mornings?

**Senator Beaudoin:** Wednesday and Thursday are impossible. Tuesday afternoon is impossible. What is wrong with Monday afternoon?

**Senator Kirby:** I do not like to be in town if I do not have to be here.

**Senator Carstairs:** What about Tuesday morning from 8:30 to 10:30?

**Senator Kirby:** That is no problem for me.

**The Chairman:** That is very difficult for Senator Keon because that is when he normally does his surgery.

**Senator Kirby:** Since we will not have many meetings, perhaps we should canvass people to figure out a time that works rather than prescribe a time because, in any given week, schedules can change.

**Senator Beaudoin:** If we do not have many meetings, I will accept Tuesday morning. Tuesday is a terrible day for me. From 12:00 p.m. to 6:00 p.m. is full.

**Senator Pépin:** It is the same thing for me, but the only time I have is Tuesday morning. The rest of the week is full.

**Senator Beaudoin:** Let us accept that, then.

**Senator Corbin:** You have agreed to operate without the full committee present. Your main task is to collect information. Therefore, if some people cannot show up on a particular day or morning or afternoon the committee will still be functional and I think it should proceed so as not to drag this thing out forever.

**The Chairman:** Let us decide on 8:30 a.m. to 10:30 a.m. Tuesdays.

**La présidente:** Il est question des dépenses de voyage et d'hébergement des témoins, et non des sénateurs.

**Le sénateur Beaudoin:** Très bien. J'en fais la proposition.

**La présidente:** Honorables sénateurs, êtes-vous d'accord pour adopter la motion?

**Des voix:** D'accord.

**La présidente:** Adoptée.

Pour ce qui est de l'heure des séances régulières du sous-comité, le comité des affaires sociales se réunit à 15 h 30 le mercredi et à 11 h 30 le jeudi. Dans certains cas, il y a conflit avec le comité sénatorial permanent des affaires juridiques et constitutionnelles. Je propose de limiter le nombre de séances que nous aurons au début, mais d'essayer de réserver le lundi après-midi. Il va de soi que vous seriez avertis longtemps à l'avance. Cela vous convient-il?

**Le sénateur Beaudoin:** Le lundi après-midi?

**Le sénateur Kirby:** Le lundi après-midi, cela ne me plaît guère. En effet, c'est le seul jour de la semaine où je ne suis pas tenu d'être ici. Que pensez-vous du mardi matin?

**Le sénateur Beaudoin:** Le mercredi et le jeudi, c'est impossible. Le mardi après-midi, c'est impossible également. Qu'est-ce qui ne va pas le lundi après-midi?

**Le sénateur Kirby:** Je n'aime pas tellement venir en ville, à moins d'y être obligé.

**Le sénateur Carstairs:** Et le mardi matin de 8 h 30 à 10 h 30?

**Le sénateur Kirby:** Cela ne me pose aucun problème.

**La présidente:** Ce sera très difficile pour le sénateur Keon car il est normalement en salle d'opération à cette heure-là.

**Le sénateur Kirby:** Étant donné que nous n'aurons pas tellement de réunions, nous pourrions peut-être sonder les membres et trouver un créneau au lieu de prescrire une heure en particulier car d'une semaine à l'autre, les horaires peuvent changer.

**Le sénateur Beaudoin:** Si nous n'avons pas tellement de séances, j'accepterai le mardi matin. Le mardi est un jour terrible pour moi. Je suis pris de midi à 18 heures.

**Le sénateur Pépin:** C'est la même chose pour moi, mais le seul temps dont je dispose est le mardi matin. Le reste de la semaine est complet.

**Le sénateur Beaudoin:** Entendons-nous là-dessus, dans ce cas.

**Le sénateur Corbin:** Vous avez convenu de fonctionner sans que tous les membres du comité soient présents. La tâche principale du sous-comité est de recueillir de l'information. Par conséquent, si certaines personnes ne peuvent être présentes un jour en particulier ou encore une matinée ou un après-midi, le comité ne sera pas empêché de fonctionner. Je pense qu'il devrait aller de l'avant pour ne pas faire traîner les choses en longueur.

**La présidente:** Entendons-nous sur le mardi de 8 h 30 à 10 h. 30.

**Senator Beaudoin:** I cannot accept that time because I am on the other side of the river. We have a bridge to cross and it is extremely difficult to do so at that time of the morning; however, 9:00 a.m. is acceptable.

**The Chairman:** We will meet from 9:00 a.m. to 11:00 a.m., then.

Honourable senators, I have submitted two budgets to you. I should like to pass the first one today so that we can then go to the Standing Committee on Internal Economy, Budgets and Administration. I wanted you to see the full study. As you can see, the costs are very modest. The budget for March 31, 2000, is for \$7,890 and from June 6, 2000, is for \$3,100. I suspect that we will not spend that kind of money on meals if we are meeting from 9:00 a.m. to 11:00 a.m. in the morning.

**Senator Kirby:** Those two budgets are so reasonable, I am happy to move a motion to accept both. We are talking about only \$11,000.

**The Chairman:** Is it your pleasure, honourable senators to adopt the motion?

**Hon. Senators:** Agreed.

**The Chairman:** Carried.

Now, let us get to the most important part of the meeting, namely, the work plan, which is in front of you. The terms of reference have been approved by the Senate. Let us make it very clear among honourable senators here that this committee has no intention of reviewing the decisions that were made on euthanasia and assisted suicide. We will not look at those recommendations. We will focus our review here on the unanimous recommendations of the committee — that is, the unanimous recommendations on the withholding and withdrawing of life-support treatment, on palliative care, on advance directives, on sedation practices, and on anything that was a unanimous recommendation in the report. We will be asking for an update.

Senator Corbin asked about the kinds of witnesses we will have. I should like you to give authority to the staff to set up for us, early in February, a series of witnesses on the state of palliative care in Canada so that we can hear if in the last five years more service has been available to patients across the country. I want to find out if any better medical training is going on now. We learned that there was little or no training in pain control and sedation practices at the universities. I should like to be able to contact some of those earlier witnesses, like Dr. MacDonald from Montreal, and find out what they know today about what is happening in our medical schools with respect to the training of physicians.

**Senator Beaudoin:** I am glad to see how it will work because I have always said that we should implement all of our unanimous decisions as soon as possible. I have agreed with that since the

**Le sénateur Beaudoin:** Cette heure ne me convient pas car j'habite de l'autre côté de la rivière. Il me faut traverser le pont, et c'est extrêmement difficile à l'heure de pointe, le matin. Cela dit, 9 heures c'est acceptable.

**La présidente:** Nous allons donc nous réunir de 9 heures à 11 heures.

Honorables sénateurs, je vous ai soumis deux budgets. J'aimerais que nous adoptions le premier aujourd'hui pour que nous puissions ensuite le présenter au comité permanent de la régie interne, des budgets et de l'administration. Je voulais que vous voyiez l'étude intégrale. Comme vous pouvez le constater, les coûts sont très modestes. Le budget pour le 31 mars 2000 s'élève à 7 890 \$ et à compter du 6 juin 2000, on prévoit 3 100 \$. J'ai l'impression que nous ne dépenserons pas cet argent pour les repas si nous nous réunissons de 9 heures à 11 heures le matin.

**Le sénateur Kirby:** Ces deux budgets sont tellement raisonnables que je suis très heureux d'avoir présenté la motion d'adoption. En fait, cela ne représente que 11 000 \$.

**La présidente:** Honorables sénateurs, êtes-vous d'accord pour adopter la motion?

**Des voix:** D'accord.

**La présidente:** Adoptée.

Passons maintenant à la partie la plus importante de la séance, c'est-à-dire notre plan de travail, que vous avez devant vous. Notre mandat a été approuvé par le Sénat. Je veux qu'une chose soit très claire entre nous, soit que notre comité n'a pas l'intention de passer en revue les décisions qui ont été prises au sujet de l'euthanasie et du suicide assisté. Nous n'allons pas examiner ces recommandations. Notre examen s'attachera aux recommandations unanimes du comité, c'est-à-dire les recommandations unanimes concernant l'abstention et l'interruption de traitement de survie, les soins palliatifs, les directives préalables, les pratiques de sédation, autrement dit tout ce qui a fait l'objet d'une recommandation unanime dans le rapport. Nous allons demander une mise à jour.

Le sénateur Corbin a posé une question au sujet des témoins que nous entendrons. J'aimerais donner à l'équipe de recherche l'autorisation de dresser pour nous, au début de février, une liste de témoins sur l'état des soins palliatifs au Canada pour que nous puissions savoir si, depuis cinq ans, il y a davantage de services de ce genre disponibles pour les patients canadiens. Je veux déterminer s'il y a une meilleure formation médicale dans ce domaine à l'heure actuelle. Nous avons appris qu'il y avait peu ou pas de formation dans le domaine du contrôle de la douleur et des pratiques sédatives à l'université. Je voudrais que nous puissions communiquer avec certains des témoins antérieurs, comme le docteur MacDonald de Montréal. Ainsi, nous pourrions savoir ce qui se passe à l'heure actuelle dans les facultés de médecine pour ce qui est de la formation des futurs médecins.

**Le sénateur Beaudoin:** Je suis heureux de savoir comment nous fonctionnerons car j'ai toujours dit que nous devrions mettre en oeuvre toutes nos décisions unanimes le plus tôt possible. Je



beginning. I am ready to participate in that work. How long will this subcommittee take? Will it take one or two years?

**The Chairman:** The date of filing our report is June 6.

**Senator Beaudoin:** As early as June?

**The Chairman:** That will be the five-year anniversary.

**Senator Beaudoin:** Are we to study all of our unanimous decisions?

**The Chairman:** That is right.

**Senator Beaudoin:** I have no problem with that.

**The Chairman:** I do not want to rehash the report. We did a thorough job.

**Senator Beaudoin:** We should at least start with the unanimous part.

**Senator Corbin:** You said earlier that we are now putting things on the table and yet, in the transportation and communications budget, you have three items concerning video conferences. You have Australia, the Netherlands and Oregon. Why are the Netherlands and Oregon on there if we are to deal with the unanimous recommendations? Those are controversial aspects.

**The Chairman:** The first of the terms of reference for the committee, which were approved by the Senate, was the progress on the implementation of the unanimous recommendations made in the report. That was the first thing I addressed. The second term of reference involves the developments in Canada respecting the issues dealt with in the report. That specifically deals with areas such as advanced directives. More provinces have passed advance directive legislation. The other thing I should like today would be approval for staff to write to the provinces so that we can have an update from them on the status of that kind of information. The third reference involves developments in foreign jurisdictions respecting the issues dealt with in the report.

This is without judgment, Senator Corbin. This document is now being used in medical schools across the country. Senator Kinsella indicated that he is using it. However, some of the information about what is going on in foreign jurisdictions is no longer accurate. I do not think we need to have particular witnesses on this. Ms Dunsmuir has already covered it — that is, if you get a chance to read her report with respect, for example, to the northern territory of Australia. We have included Oregon, the Netherlands and Australia in our budget so that if we are not satisfied with the information that the researchers have been able to obtain with respect to what is happening in those places, we will have the leeway to conduct a video conference with them in order to have further information that we can add to the report. However, I want to make it clear that addressing what is happening in foreign jurisdictions would not be for the purpose of reviewing the recommendations; it would be only to update the information.

**Senator Beaudoin:** Another aspect also strikes me. This is partly provincial jurisdiction. When we studied this in 1994-95, we were very prudent not to invade the provincial field. We will

suis d'accord avec ce principe depuis le début. Je suis prêt à participer à ce travail. Combien de temps prendra le sous-comité? Un an ou deux?

**La présidente:** Nous devons soumettre notre rapport le 6 juin.

**Le sénateur Beaudoin:** Dès le mois de juin?

**La présidente:** Cela coïncide avec l'anniversaire de cinq ans.

**Le sénateur Beaudoin:** Allons-nous étudier toutes nos décisions unanimes?

**La présidente:** C'est exact.

**Le sénateur Beaudoin:** Je n'ai aucune objection.

**La présidente:** Nous ne voulons pas revenir sur le rapport. Nous avons fait un travail exhaustif.

**Le sénateur Beaudoin:** Nous devrions à tout le moins commencer par la partie unanime.

**Le sénateur Corbin:** Vous avez dit tout à l'heure que nous mettions maintenant les choses sur la table et pourtant, dans le budget des transports et des communications, il y a trois points concernant des vidéoconférences, avec l'Australie, les Pays-Bas et l'Orégon. Pourquoi a-t-on inclus les Pays-Bas et l'Orégon, si nous devons traiter des recommandations unanimes? Il s'agit là d'aspects controversés.

**La présidente:** La première partie du mandat du comité, qui a été approuvé par le Sénat, consiste à évaluer les progrès réalisés dans la mise en oeuvre des recommandations unanimes du rapport. C'est la première chose dont j'ai parlé. La deuxième partie du mandat concerne l'évolution de la situation au Canada pour ce qui est des questions évoquées dans le rapport. Cela porte précisément sur des domaines comme les directives préalables. La plupart des provinces ont adopté une loi concernant les directives préalables. Une autre chose que je veux faire aujourd'hui, c'est autoriser un membre du personnel à communiquer par écrit avec les autorités provinciales pour que nous puissions obtenir une mise à jour sur le statut de ce genre d'information. La troisième partie du mandat porte sur l'évolution de la situation à l'étranger.

Cela ne suppose aucun jugement, sénateur Corbin. Ce document est maintenant utilisé dans les facultés de médecine dans tout le pays. Le sénateur Kinsella nous a dit qu'il l'utilise. Cependant, certains des renseignements concernant la situation à l'étranger ne sont plus exacts. Mme Dunsmuir en a déjà parlé — si vous avez l'occasion de lire son rapport concernant le territoire septentrional de l'Australie. Nous avons inclus l'Orégon, les Pays-Bas et l'Australie dans notre budget pour que, si nous ne sommes pas satisfaits des renseignements que les attachés de recherche auront pu obtenir concernant ce qui se passe dans ces pays, nous puissions avoir la marge de manoeuvre voulue pour organiser une vidéoconférence avec les autorités responsables et ainsi obtenir davantage d'informations que nous pourrions ajouter au rapport. Cependant, je tiens à expliquer clairement que toutes les communications avec les autorités étrangères ne s'inscriront pas dans notre examen des recommandations; elles auront uniquement pour but de recueillir de l'information.

**Le sénateur Beaudoin:** Un autre aspect me frappe. Il s'agit d'un domaine qui relève partiellement de la compétence des provinces. Lorsque nous avons fait notre étude, en 1994-1995,

continue in the same manner, but nothing precludes us from giving our conclusions and our suggestions. However, we must take into account that part of it deals with health and part of that is regulated provincially. We never invaded the provincial field, and I hope that will continue.

**The Chairman:** Absolutely. I should like two motions. The first would be:

That staff be directed to write to the provinces about updating information in those provinces with respect to the unanimous recommendations found in the report.

**Senator Kirby:** I so move.

**The Chairman:** Is it your pleasure, honourable senators, to adopt the motion?

**Hon. Senators:** Agreed.

**The Chairman:** Carried.

Second, I should like a motion to authorize the staff to put together a list and contact witnesses with respect to the issues in the unanimous recommendations and the progress of those unanimous recommendations — that is, witnesses with respect to palliative care and with respect to the withholding and withdrawing of life-support treatment and those kinds of things.

**Senator Corbin:** I thought about witnesses well before the meeting. Why not ask the Minister of Health, Mr. Rock, to appear before this committee? It would be interesting for two reasons. He would be suspected of being one of the principal actors on our recommendations, certainly with respect to palliative care and with his conversations with the provinces and with financing. Furthermore, he was Minister of Justice and he appeared before this committee when we dealt with these controversial issues. He could probably give us the benefit of his overall views on two sides of the question.

**The Chairman:** There are two ministers from whom I should like hear with respect to any progress that has been made: the Minister of Health, who was the Minister of Justice when the report was prepared, and the current Minister of Justice.

**Senator Kirby:** As would I.

**The Chairman:** I should like authorization from the committee to outline for those ministers, in a detailed letter, the kinds of things we would like them to speak to us about. I would use the basis of the unanimous recommendations for those letters. There is no point in saying, "We want you to come." I should like to say, "We would like you to come to talk about the following." That is to say, I should like to be very point specific, based on the unanimous recommendations contained in the report.

nous avons été très prudents afin de ne pas nous immiscer dans un champ de responsabilité provincial. Nous continuerons à agir de la même façon, mais rien ne nous empêche d'énoncer nos conclusions et nos suggestions. Cependant, nous devons tenir compte de cet aspect qui rejoint la santé et qui relève de la responsabilité des provinces. Nous ne nous sommes jamais ingérés dans un domaine de compétence provinciale, et j'espère que cela continuera.

**La présidente:** Absolument. J'aimerais qu'on présente deux motions. La première se lirait comme suit:

Que l'on demande au personnel de communiquer avec les autorités provinciales afin d'obtenir une mise à jour de l'information concernant leur province au sujet des recommandations unanimes du rapport.

**Le sénateur Kirby:** J'en fais la proposition.

**La présidente:** Honorables sénateurs, êtes-vous d'accord pour adopter la motion?

**Des voix:** D'accord.

**La présidente:** Adoptée.

Deuxièmement, je voudrais qu'on présente une motion autorisant le personnel à dresser une liste et à communiquer avec des témoins au sujet des recommandations unanimes et des progrès réalisés quant à leur mise en œuvre. Autrement dit, des témoins qui nous parleraient des soins palliatifs, ainsi que de l'abstention et de l'interruption d'un traitement de survie, et cetera.

**Le sénateur Corbin:** J'ai réfléchi au sujet des témoins bien avant la séance. Pourquoi ne pas demander au ministre de la Santé, M. Rock, de comparaître devant le comité? Ce serait intéressant pour deux raisons. Je suppose que ce sera l'un des principaux acteurs amenés à agir au sujet de nos recommandations, certainement en ce qui a trait aux soins palliatifs, ainsi qu'aux entretiens avec les provinces et au financement. En outre, lorsqu'il était titulaire du ministère de la Justice, il a comparu devant le comité au moment de notre étude de ces questions épineuses. Il pourrait sans doute nous faire bénéficier de son opinion générale pour ce qui est des deux aspects de la question.

**La présidente:** Il y a deux ministres que j'aimerais entendre au sujet des progrès réalisés: le ministre de la Santé, qui était le ministre de la Justice lorsque le rapport a été rédigé, et l'actuelle ministre de la Justice.

**Le sénateur Kirby:** Tout comme moi.

**La présidente:** J'aimerais obtenir du comité l'autorisation d'expliquer à ces ministres, dans une lettre détaillée, ce dont nous aimerions qu'ils nous parlent. Je me servais des recommandations unanimes pour rédiger ces lettres. Il est inutile de leur dire: «Nous voulons que vous veniez comparaître.» J'aimerais préciser: «Nous voudrions que vous veniez nous parler de telle ou telle chose.» Autrement dit, j'aimerais que leur intervention soit très précise, qu'elle se fonde sur les recommandations unanimes contenues dans le rapport.



**Senator Beaudoin:** Mr. Rock has the advantage of being not only the Minister of Health but also a good jurist.

**The Chairman:** Is that agreed, honourable senators?

**Hon. Senators:** Agreed.

**The Chairman:** Carried.

Do we have authority for the staff to begin to gather the list of witnesses so that we can begin in February?

**Hon. Senators:** Agreed.

**The Chairman:** Carried.

It is not my intention to call you back to a meeting before February. However, I may be in touch with you, including members of the former committee, so that you have some guidance as to where we are going.

**Senator Corbin:** I would appreciate that.

**The Chairman:** I will also give you copies of any letters that I send to ministers.

**Senator Beaudoin:** Have you had discussions with Senator DeWare as well?

**The Chairman:** Yes. She hopes to be an active participant in the committee, as do Senator Keon and Senator Lavoie-Roux — that is, if her health improves and she returns. There will then be six of the seven members of the original committee who, hopefully, will be able to contribute.

**Senator Corbin:** I thought a lot about former Senator Joan Neiman, who was chair of the original committee. I have met her on rare occasions since the tabling of that report. Apparently she has received a lot of mail and comment about the report, but we are not privy to that. It was addressed to her and she has kept it for herself. I never received that kind of feedback. On the assumption that she is still active, would it be beneficial for the committee to hear from her?

**The Chairman:** I would be delighted to hear from Senator Neiman. I have a wonderful suggestion that we invite her to come and share with us what she has heard over the last five years.

**Senator Corbin:** That is just a suggestion.

**The Chairman:** It is a wonderful suggestion.

The committee adjourned.

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OTTAWA, Monday, February 14, 2000

The Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 2:01 p.m. to examine the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide entitled, "Of Life and Death".

**Senator Sharon Carstairs** (*Chairman*) in the Chair.

**Le sénateur Beaudoin:** M. Rock a l'avantage d'être non seulement le ministre de la Santé, mais également un excellent juriste.

**La présidente:** Est-ce d'accord, honorables sénateurs?

**Des voix:** D'accord.

**La présidente:** D'accord.

Ai-je votre autorisation de demander au personnel de commencer à dresser la liste des témoins pour que nous puissions commencer en février?

**Des voix:** D'accord.

**La présidente:** Adopté.

Je n'ai pas l'intention de convoquer de séances avant février. Cependant, je demeurerai sans doute en contact avec vous, y compris les membres de l'ancien comité, pour que vous ayez une idée de notre orientation.

**Le sénateur Corbin:** Je l'apprécierais.

**La présidente:** Je vous ferai distribuer également des copies des lettres que j'enverrai aux ministres.

**Le sénateur Beaudoin:** Avez-vous parlé au sénateur DeWare?

**La présidente:** Oui. Elle espère participer activement aux travaux du comité, tout comme le sénateur Keon et le sénateur Lavoie-Roux, en supposant, évidemment, que son état de santé s'améliore et qu'elle revienne. À ce moment-là, il y aura six des sept membres du comité original qui seront en mesure d'apporter leur contribution.

**Le sénateur Corbin:** J'ai pensé souvent à l'ex-sénateur Joan Neiman, qui assumait la présidence du comité original. Je l'ai rencontrée à quelques rares occasions depuis le dépôt du rapport. Apparemment, elle a reçu énormément de courrier et de commentaires au sujet du rapport, mais nous n'en avons pas pris connaissance. Cette correspondance lui était adressée et elle l'a conservée par-devers elle. Je n'ai jamais reçu ce genre de rétroaction. En supposant qu'elle soit toujours active, serait-il utile pour le comité de l'entendre?

**La présidente:** Je serais ravie d'entendre le sénateur Neiman. Je propose que nous l'invitions à comparaître et à partager avec nous les réactions qu'on lui a communiquées depuis cinq ans.

**Le sénateur Corbin:** Ce n'est qu'une suggestion.

**La présidente:** C'est une merveilleuse suggestion.

La séance est levée.

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OTTAWA, le lundi 14 février 2000

Le sous-comité de la mise à jour de «de la vie et de la mort» du comité sénatorial permanent des affaires sociales, des sciences et de la technologie se réunit aujourd'hui à 14 h 01 pour étudier les faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé «De la vie et de la mort».

**Le sénateur Sharon Carstairs** (*présidente*) occupe le fauteuil.

[English]

**The Chairman:** Today we begin the first in a series of hearings under our mandate to update the unanimous recommendations of the 1995 Special Senate Committee report on euthanasia and assisted suicide entitled, "Of Life and Death".

I would remind honourable senators and witnesses that this committee is not reopening the debate on assisted suicide and euthanasia, it is dealing strictly with the areas of the report where the original committee made unanimous recommendations. I would ask that everyone bear this in mind as we proceed through the hearings.

Three witnesses were invited today to provide us with an overview of the issues at hand. Regrettably, Professor Keyserlingk, who was to join us from the Biomedical Ethics Unit, Faculty of Medicine at McGill University, is snowbound in Montreal and cannot be with us. Both witnesses who are here are well known to members of the committee. Professor Jocelyn Downie worked with us for many months on the original report. Professor Barney Sniderman is also here.

**Professor Jocelyn Downie, Health Law Institute, Dalhousie University:** Thank you, honourable senators, for the invitation to participate this afternoon. I applaud you for undertaking the task of updating the Senate report which was completed five years ago.

I was asked to provide an overview of the progress made over the past five years with respect to the unanimous recommendations made by the Special Senate Committee on Euthanasia and Assisted Suicide in "Of Life and Death." Given the time constraints, I have set myself two limited tasks: first, to update the legal status sections of "Of Life and Death" by reporting on any changes to the legal status and any significant legal events or developments for each of the categories of assisted death; second, to report on the status of unanimous legal recommendations made in "Of Life and Death".

I will first look at pain control and sedation practices and changes in the legal status. Quite simply, there have not been any. There have been a few significant legal events or developments. In 1996, Senator Carstairs introduced a bill to clarify the law with respect to withholding pain control and sedation practices. This bill died when the last federal election was called.

Then Senator Lavoie-Roux introduced a bill with similar intention. It died with the first session of the 36th Parliament.

In 1999, Senator Carstairs introduced another bill, again designed to clarify the law with respect to pain control and sedation practices. We are waiting quite eagerly to see what will happen with that bill.

[Traduction]

**La présidente:** Comme le prévoit notre mandat, nous entamons aujourd'hui des audiences destinées à mettre à jour les recommandations qu'a prises à l'unanimité le comité sénatorial spécial de 1995 dans son rapport sur l'euthanasie et l'aide au suicide intitulé «De la vie et de la mort».

Je voudrais rappeler aux sénateurs et aux témoins que notre comité ne désire pas ouvrir le débat sur l'aide au suicide et sur l'euthanasie, mais qu'il veut s'en tenir strictement aux parties du rapport qui ont fait l'objet de recommandations unanimes de la part du premier comité. J'espère que l'on tiendra compte de cette mise en garde tout au long des audiences.

Nous avons invité aujourd'hui trois témoins qui devaient nous éclairer sur les grands enjeux dont nous sommes saisis. Malheureusement, le professeur Keyserlingk, de l'Unité d'éthique biomédicale de la Faculté de médecine de l'université McGill, ne peut se joindre à nous parce qu'il est retenu par la neige à Montréal. Les deux autres témoins qui ont été invités sont bien connus des membres de notre comité. Il s'agit du professeur Jocelyn Downie, qui nous a aidés pendant plusieurs mois pendant la préparation du premier rapport, et du professeur Barney Sniderman.

**Mme Jocelyn Downie, professeure, Health Law Institute, Université Dalhousie:** Honorables sénateurs, merci beaucoup de m'avoir invitée cet après-midi à prendre part à vos travaux. Je vous félicite de vous être engagés à mettre à jour le rapport sénatorial terminé il y a maintenant cinq ans.

On m'a demandé de faire un survol des progrès accomplis depuis cinq ans eu égard aux recommandations qu'avaient faites à l'unanimité le comité sénatorial spécial sénatorial sur l'euthanasie et l'aide au suicide dans son rapport intitulé «De la vie et de la mort». Étant donné les contraintes de temps, je me suis limitée à deux tâches: d'abord, je veux faire le point sur le statut juridique de certaines parties du rapport «De la vie et de la mort» en vous signalant les changements juridiques qui sont survenus, s'il y a eu, et je veux aussi vous signaler toute évolution qui aurait pu survenir dans chacune des catégories de l'aide au suicide; en second lieu, je voudrais vous expliquer où en sont les recommandations d'ordre juridique qui ont été faites à l'unanimité dans le rapport «De la vie et de la mort».

Je vais d'abord aborder les pratiques de sédation et de traitement de la douleur et les changements dans le milieu juridique. À vrai dire, il n'y en a pas eu. On peut à peine parler de quelques changements significatifs d'ordre juridique. En 1996, le sénateur Carstairs déposait un projet de loi devant préciser dans la loi les questions d'abstention de traitement de la douleur et de pratiques de sédation. Le projet de loi est mort au *Feuilleton* au moment du déclenchement des dernières élections fédérales.

Puis le sénateur Lavoie-Roux a déposé un autre projet de loi aux mêmes fins, qui est mort au *Feuilleton* à son tour, lors de la première session de la 36<sup>e</sup> législature.

En 1999, le sénateur Carstairs déposait un autre projet de loi destiné à nouveau à faire préciser dans la loi des questions concernant les pratiques de traitement de la douleur et de sédation. Nous avons hâte de voir ce qu'il adviendra de ce projet de loi.



As to the status of the unanimous legal recommendations with respect to pain control and sedation practices, they simply have not been acted upon. The Criminal Code has not been amended to clarify the practice of providing treatment for the purpose of alleviating suffering that may shorten life.

Turning now to changes in the legal status, there has been none at the federal level. Provincially, though, we have seen some movement. For instance, the Ontario Health Care Consent Act of 1996 now provides for a clear, statutorily protected right to refuse potentially life-sustaining treatment.

There have also been some significant developments or events on which one might comment. Again we refer back to Senator Carstairs' 1996 bill which was designed to clarify the law with respect to withholding and withdrawal of life-sustaining treatment, followed by Senator Lavoie-Roux's bill, again with similar intentions, and now the 1999 bill. Those three bills all deal with pain control and sedation practices and withholding or withdrawal of life-sustaining treatment.

Let me take you from the general, with respect to withholding and withdrawal, to some specific categories of people and developments with respect to those categories of people in the arena of withholding and withdrawal. The Supreme Court of Canada considered the common-law status of refusals of treatment for immature minors in the case of *Sheena B.* While it was not so clear when the Senate committee delivered "Of Life and Death", it is now clear that, where withholding and withdrawal of potentially life-sustaining treatment is in the child's best interests, the parents have the authority to refuse the treatment and their refusal must be respected. However, where the treatment is in the child's best interests, then the parental refusal will be overridden by the state.

The second group of individuals of concern is mature minors. Since the Senate report on euthanasia and assisted suicide, there has been some legislative and common-law activity in the arena of mature minors. However, there is still little clear guidance to be found in most provincial legislation or in the common-law. In particular, it is not yet clear whether minors who understand the nature and the consequences of the decision to be made should have their decisions respected, full stop, or should only have their decisions respected when what they are seeking to do or not do is actually considered to be in their best interests by a third party — the health care professional or the court.

The third group within "withholding and withdrawal" is those who would seek to perform unilateral withholding or withdrawal of life-sustaining treatment. This takes us into the futility debate. In the past few years, two cases have arisen which raise the question of what should happen when surrogate decision makers want treatment and the health care team believes that the treatment would not be in the incompetent person's best interests.

Quant à ce qu'il est advenu des recommandations d'ordre juridique prises à l'unanimité par le dernier comité eu égard au traitement de la douleur et aux pratiques de sédation, elles sont tout simplement restées lettre morte. Le Code criminel n'a pas été modifié pour apporter des précisions à la pratique de traitement de la douleur dans le but de soulager la souffrance, même si cela pouvait abrégé la vie du patient.

Passons maintenant aux modifications du statut juridique: il n'y a rien eu de fait au palier fédéral. Dans les provinces, toutefois, les choses ont bougé quelque peu. Ainsi, la loi ontarienne de 1996 intitulée «Health Care Consent Act» prévoit désormais que le patient a le droit clairement énoncé de refuser un traitement qui pourrait assurer sa survie.

Il y a également plusieurs événements d'importance qui sont survenus et que j'aimerais commenter. Je me reporte à nouveau au projet de loi de 1996 du sénateur Carstairs dans lequel elle voulait faire préciser dans la loi des questions concernant l'abstention et l'interruption du traitement de survie, puis au projet de loi du sénateur Lavoie-Roux, dont les objectifs étaient les mêmes, puis enfin au projet de loi de 1999. Ces trois projets de loi portaient tous sur le traitement de la douleur et sur les pratiques de sédation ainsi que sur l'abstention ou l'interruption du traitement de survie.

Laissez-moi passer de l'aspect général de l'abstention et de l'interruption de traitement à certaines catégories spécifiques de gens ainsi qu'à des événements survenus concernant ces catégories de gens touchés par les questions d'interruption et d'abstention. La Cour suprême du Canada s'est penchée sur l'interprétation en common law du refus de traitement dans le cas des mineurs non mûrs, dans l'affaire *Sheena B.* Alors que la situation n'était pas aussi claire que cela à l'époque où le comité sénatorial a publié son rapport, il est désormais clair que lorsque l'abstention et l'interruption de traitement de survie est dans l'intérêt de l'enfant, les parents ont le droit de refuser le traitement, et leur refus doit être respecté. Toutefois, lorsque le traitement est, au contraire, dans l'intérêt de l'enfant, le refus des parents peut-être annulé par l'État.

Le deuxième groupe d'individus qui nous préoccupent ici, ce sont les mineurs mûrs. Depuis la publication du rapport sénatorial sur l'euthanasie et l'aide au suicide, il s'est produit certains événements d'ordre législatif dans le domaine du common law qui touchent les mineurs mûrs. Toutefois, la plupart des lois provinciales ou le common law ne nous éclairent pas beaucoup là-dessus. De façon plus particulière, il n'a pas encore été établi clairement si les mineurs qui comprennent la nature et les conséquences de leur décision devraient pouvoir faire respecter leur choix, ou si leur décision de se faire traiter ou non doit être respectée uniquement si une tierce partie — le professionnel de la santé ou le tribunal — considère que c'est dans l'intérêt véritable du patient.

Le troisième groupe auquel s'appliquent l'abstention et l'interruption, c'est le groupe d'individus qui cherchent unilatéralement à interrompre ou à refuser le traitement de survie. Or, le débat devient alors futile. Au cours des dernières années, deux cas sont survenus qui posent la question de ce qui devrait arriver lorsque les fondés de pouvoir demandent le traitement, mais que l'équipe médicale est d'avis que le traitement ne serait

It is a flip of the usual withholding/withdrawal situation. I believe Barney will be discussing these cases in details, so I will not review them here. The factual details are in the written brief which I will be supplying to the committee.

For the purposes of the review today, to set the stage for you, it is sufficient to note that there have been two highly published and controversial cases in this area. There has also been a great deal of discussion of the issue of unilateral withholding and withdrawal of the potentially life-sustaining treatment. Thus, this issue, which was merely lurking in the background in 1995, has come to the fore now and is in need of attention.

That takes us to the status of the legal recommendations with respect to withholding and withdrawal. The Criminal Code has not been amended. Necessary legislation has not been enacted in order to explicitly recognize and clarify the circumstances in which the withholding/withdrawal of life-sustaining treatment is legally acceptable.

Regarding advance directives, since releasing "Of Life and Death", several provinces have moved to introduce advance directives legislation. Seven provinces and one territory have now passed and proclaimed legislation; two provinces have passed but not yet proclaimed their legislation, despite the fact that one piece of legislation dates back to 1993; and one province and two territories still have no legislation at all with respect to advance directives.

There have been no significant legal events or developments with respect to advance directives, so you could say that the legal recommendations are "partially done" and they are "not done." They are "partially done" in that some but not all provinces and territories that did not have advance directives legislation have adopted such legislation, as recommended by the committee. However, the provinces and territories have not collectively established a protocol to recognize advance directives constructed in one province or territory which require to be utilized in another province or territory.

I would turn now to assisted suicide. There have been no changes in the legal status of assisted suicide in Canada. There have, however, been several cases of note. In October of 1995, Mary Fogarty was convicted of assisting in the suicide of a friend. The Crown alleged, and the jury agreed, that Mary Fogarty provided Brenda Barnes, a diabetic, with syringes and insulin and wrote Barnes' suicide note for her. Fogarty was convicted and sentenced to three years probation and 300 hours of community service. Thus, she became the first person convicted and the first person in over 30 years to have been charged under section 241(b) of the Criminal Code. In June 1996, Dr. Maurice Genereux was charged under 241(b) of the Criminal Code for assisting with the suicide of a patient. In May 1997, additional charges were laid and he ultimately faced charges that included aiding or abetting suicide and counselling to commit suicide, as well as the straightforward assisted suicide. Dr. Genereux was accused of prescribing drugs to two patients who were HIV positive. One ultimately committed suicide; the other attempted suicide. This was the first time a physician had been charged with that crime in

pas dans l'intérêt véritable du patient incapable de décider. C'est l'envers de la situation que l'on trouve généralement dans les cas d'abstention et d'interruption de traitement. Comme mon collègue, Barney Sneiderman, est censé vous en parler en détail, je m'abstiendrai de m'y attarder. Vous trouverez tout ce qu'il vous faut dans le mémoire que je ferai tenir au comité.

Pour nos fins aujourd'hui, et pour bien vous exposer la situation, qu'il me suffise de vous signaler qu'il y a eu dans ce domaine deux causes extrêmement médiatisées et controversées. On a abondamment discuté de la question de l'abstention et de l'interruption unilatérales de tout traitement de survie. Par conséquent, cette question qui était en veilleuse en 1995 est maintenant arrivée à l'avant-plan et doit être abordée.

Cela m'amène au statut des recommandations d'ordre juridique concernant l'abstention et l'interruption. Le Code criminel n'a pas été amendé. Aucune loi en ce sens n'a été adoptée en vue de reconnaître explicitement cette situation et en vue de préciser les circonstances dans lesquelles l'abstention ou l'interruption d'un traitement de survie est acceptable du point de vue juridique.

Depuis la publication du rapport «De la vie et de la mort», plusieurs provinces ont choisi de présenter des mesures législatives sur les directives préalables. Sept provinces et un territoire ont aujourd'hui adopté et promulgué des lois en ce sens; deux provinces ont déjà adopté une loi qui n'est pas encore promulguée, même si dans l'un des cas la loi remonte à 1993; enfin, une province et deux territoires n'ont aujourd'hui encore rien fait pour traiter des directives préalables.

Comme il n'y a eu aucun événement d'ordre juridique d'envergure touchant les directives préalables, on pourrait dire que les recommandations d'ordre juridique du comité ont été «partiellement suivies» ou «pas du tout suivies». Elles ont été partiellement suivies en ce que certaines provinces et certains territoires qui n'avaient aucune loi sur les directives préalables en ont adopté une depuis, tel que le recommandait le comité. Toutefois, les provinces et territoires pris collectivement n'ont pas souscrit à un protocole qui leur permettrait d'appliquer les directives préalables acceptées ailleurs.

Passons maintenant à l'aide au suicide. La situation juridique entourant l'aide au suicide n'a pas changé au Canada. Toutefois, il faut signaler plusieurs cas qui nous intéressent ici. En octobre 1995, Mary Fogarty a été reconnue coupable d'avoir aidé une amie à se suicider. Le ministère public et le jury ont jugé que Mary Fogarty avait fourni à Brenda Barnes, qui était diabétique, des seringues et de l'insuline et qu'elle avait écrit pour Barnes sa note de suicide. Fogarty a été reconnue coupable et condamnée à trois années de probation ainsi qu'à 300 heures de service communautaire. Ainsi, elle devenait la première personne en 30 ans à avoir été mise en accusation au titre de l'alinéa 241b) du Code criminel et à avoir été reconnue coupable. En juin 1996, le docteur Maurice Genereux était accusé en vertu de l'alinéa 241b) du Code criminel d'avoir aidé un patient à se suicider. En mai 1997, d'autres chefs d'accusation s'ajoutaient, et il a fini par être inculpé d'avoir encouragé son patient à se suicider, de même que de l'avoir carrément aidé à le faire. Le docteur Genereux était accusé d'avoir prescrit des médicaments à deux patients porteurs du VIH. L'un d'entre eux a fini par se suicider, alors que l'autre a



Canada. In December 1997, he pled guilty and became the first physician convicted under this provision of the Criminal Code. More recently, Burt Doerksen is scheduled to stand trial in August of 2000 on a charge of assisted suicide. It is alleged that he helped his 78-year-old wife to commit suicide by carbon monoxide in the family garage.

I will now turn to the status of legal recommendations. They are done insofar as a *laissez faire* interpretation of "done". No amendments have been made to the offence of counselling suicide under section 241(a) or (b), and section 241(b) remains intact. The recommendation was to leave things as they were, and that has been followed: they have been left as they were.

Finally, I wish to focus on euthanasia. You may ask: What about changes in the legal status? Again, there are none. There is a pattern in this presentation. What about significant legal events and developments? Again, we have had several cases of particular note. In 1993, Robert Latimer was charged with first-degree murder in the death of his daughter. He placed his severely disable daughter in the cab of his truck and, with the purpose of alleviating what he believed to be her otherwise unrelievable suffering, he asphyxiated her with carbon monoxide. Mr. Latimer was convicted of second-degree murder and was sentenced to the mandatory minimum life sentence with no possibility of parole for 10 years. After he successfully appealed his conviction to the Supreme Court of Canada, that court ordered a new trial on the grounds that the prosecution tampered with the jury by asking RCMP officers to question prospective jurors about their ethical and religious views on euthanasia and abortion.

Mr. Latimer was tried again on a charge of second-degree murder and convicted. Despite the mandatory life sentence with no possibility of parole for 10 years, he was actually sentenced to two years less a day, with one year to be spent in prison and one year under house arrest. This extraordinary sentence was possible because the trial judge granted Latimer a constitutional exemption from the mandatory minimum sentence on the grounds that such punishment would be contrary to the Charter as it would constitute cruel and unusual punishment and thus breach Latimer's section 12 rights. The Court of Appeal dismissed Mr. Latimer's appeal, allowed the Crown's appeal and imposed a mandatory minimum sentence. This case is now on appeal and should be heard by the Supreme Court of Canada any time now. I tried to find a date but could not do so. However, it was expected to be heard some time ago. We expect that to happen within the next six months.

fait des tentatives en ce sens. C'était la première fois qu'un médecin était accusé de ce crime au Canada. En décembre 1997, après avoir plaidé coupable, il devenait le premier médecin accusé aux termes de cette disposition du Code criminel. Enfin, Burt Doerksen est censé subir son procès en août 2000 sous l'inculpation d'aide au suicide. Il est accusé d'avoir aidé sa femme de 78 ans à se suicider par inhalation de monoxyde de carbone dans le garage familial.

Passons maintenant à la situation des recommandations d'ordre juridique. Ces recommandations ont été suivies par défaut, car aucun amendement n'a été apporté à l'infraction que constitue le fait de conseiller le suicide au titre des alinéas 241(a) ou b), et l'alinéa 241(b) reste inchangé. Il avait été recommandé de laisser les choses telles quelles, et c'est effectivement ce qui a été fait: elles n'ont pas été touchées.

Je vais m'attarder enfin sur l'euthanasie. Vous pourriez vous demander si les choses ont changé du point de vue juridique. Non, elles n'ont pas changé. Je sais que je me répète cet après-midi. Mais qu'en est-il d'événements survenus qui pourraient avoir une incidence du point de vue juridique? Encore une fois, il faut signaler plusieurs cas. En 1993, Robert Latimer était accusé de meurtre au premier degré pour la mort de sa fille. Il avait placé sa fille sévèrement handicapée dans la cabine de son camion et l'avait asphyxiée avec du monoxyde de carbone dans le but de soulager ce qu'il croyait être des souffrances insurmontables. M. Latimer a été reconnu coupable de meurtre au second degré et a été condamné à une peine d'emprisonnement à perpétuité avec le minimum obligatoire, sans possibilité de libération conditionnelle pendant dix ans. Après avoir interjeté appel avec succès de sa condamnation auprès de la Cour suprême, celle-ci ordonnait un nouveau procès sous prétexte que la poursuite avait suborné le jury en exigeant des agents de la GRC qu'ils demandent aux jurés potentiels ce qu'ils pensaient de l'euthanasie et de l'avortement du point de vue éthique et religieux.

M. Latimer a donc fait l'objet d'un deuxième procès sous l'inculpation de meurtre au second degré et a été reconnu coupable. Malgré la peine d'emprisonnement obligatoire à vie sans possibilité de libération conditionnelle avant dix ans, M. Latimer était en fait condamné à deux ans moins un jour d'emprisonnement, la première année devant être passée en prison et la deuxième en détention à domicile. Cette sentence extraordinaire n'a été possible que parce que le juge de première instance avait accordé à Latimer une exemption constitutionnelle de la peine minimale obligatoire sous prétexte que cette punition serait anticonstitutionnelle et constituerait une peine cruelle et inusitée allant ainsi à l'encontre des droits de M. Latimer reconnus par l'article 12 de la Charte. La Cour d'appel rejetait l'appel de M. Latimer, acceptait l'appel du ministère public et imposait au prévenu une peine minimale obligatoire. La cause est aujourd'hui en appel et devrait être entendue par la Cour suprême du Canada incessamment. J'ai voulu savoir quand, mais je n'ai pu obtenir de date. Toutefois, elle aurait dû être entendue il y a déjà quelque temps. Nous nous attendons à ce qu'elle le soit d'ici six mois.

Another case that will be familiar to you is that of Dr. Nancy Morrison. In 1997, she was charged with first-degree murder following the death of Paul Mills, a 65-year-old man with cancer of the esophagus. After numerous interventions, including many surgeries, it was determined that nothing more could be done for him. With the consent of the patient's family, all potentially life-sustaining treatment was stopped. Mr. Mills was extubated. Unfortunately, none of the drugs administered appeared to alleviate his suffering. He seemed to be in considerable pain and was gasping for breath. It was alleged that, in response to this situation of unrelievable suffering, Dr. Morrison gave Paul Mills a lethal injection of potassium chloride. Dr. Morrison was released on bail and she returned to a limited practice.

At the end of the preliminary hearing, Judge Randall Hughes concluded that a jury properly instructed could not convict the accused of the offence charged, any included offence, or any other offence and he discharged Dr. Morrison. The Crown sought an order of *certiorari* to quash Judge Randall's decision. However, because this was a review of a decision at a preliminary inquiry rather than a true appeal, the standard of review was excess of jurisdiction rather than error of law. Thus, while Justice Hamilton actually found that Judge Hughes had made an error of law, she also found that the error was within his jurisdiction to make and, therefore, it was not within her powers to grant the application. The Crown decided not to appeal Justice Hamilton's decision and this case was therefore closed with respect to criminal proceedings. The college of physicians and surgeons then investigated the matter and they chose to proceed by way of a letter of reprimand. In March 1999, Dr. Morrison signed the letter, thereby admitting the lethal injection of potassium chloride. This letter will remain in her file, but will not prevent her from practising in any way. Thus, the case was closed.

You may ask: What is the status of the legal recommendations made by the original Senate committee? Again, they were done insofar as the Senate committee did not call for anything to be done in particular. Nonvoluntary euthanasia remains a criminal offence; voluntary euthanasia remains a criminal offence; and involuntary euthanasia continues to be an offence under the present murder provisions in the Criminal Code.

However, the recommendations were "not done" insofar as a call being made to change the sentencing provisions of the Criminal Code to provide for a less severe penalty in cases of nonvoluntary euthanasia where there is the essential element of compassion or mercy. Similarly, the Criminal Code has not been amended to allow for a less severe penalty in cases of voluntary euthanasia where there is the essential element of compassion or mercy.

Vous connaissiez sans doute aussi l'affaire de la docteure Nancy Morrison. En 1997, la docteure Nancy Morrison était accusée de meurtre au premier degré à la suite de la mort de Paul Mills, un patient de 65 ans souffrant du cancer de l'oesophage. Après de nombreuses interventions, notamment des chirurgies, il avait été déterminé qu'on ne pouvait rien faire de plus pour lui. Avec le consentement de la famille du patient, on a arrêté tout traitement pouvant lui permettre de survivre et on l'a déubé. Malheureusement, aucun des médicaments qui lui étaient administrés ne semblait le soulager de ses souffrances. Il semblait souffrir énormément et avait du mal à respirer. Il a été allégué que pour soulager son patient de douleurs insurmontables la docteure Morrison avait donné à Paul Mills une injection mortelle de chlorure de potassium. La docteure Morrison fut ensuite mise en liberté sur cautionnement et s'est ensuite remise à pratiquer de façon limitée.

À la fin de l'enquête préliminaire, le juge Randall Hughes concluait qu'un jury dûment constitué ne pouvait juger l'accusée coupable de l'accusation en question, ni même de toute autre accusation, et il libérait la docteure Morrison. Le ministère public demandait ensuite un bref de *certiorari* en vue de casser le jugement du juge Randall. Toutefois, comme il s'agissait là d'un contrôle judiciaire d'un jugement rendu lors d'une enquête préliminaire plutôt que lors d'un véritable appel, le critère à établir fut celui de l'excès de compétence plutôt que de l'erreur de droit. Ainsi, même si le juge Hamilton concluait que la juge Hughes avait effectivement fait une erreur de droit, elle concluait également que l'erreur n'excédait pas sa compétence et que, par conséquent, il ne lui revenait pas d'accéder à la demande. Le ministère public décidait ensuite de ne pas interjeter appel de la décision du juge Hamilton, et on a donc terminé ainsi la poursuite au criminel. Toutefois, le Collège des médecins et chirurgiens s'est penché lui aussi sur l'affaire et a choisi à son tour d'agir en envoyant une lettre de réprimande. En mars 1999, la docteure Morrison signait la lettre et admettait ainsi qu'elle avait donné une injection mortelle de chlorure de potassium à son patient. Cette lettre est maintenant portée à son dossier, mais ne devrait pas l'empêcher de pratiquer de quelque façon que ce soit. L'affaire est donc close.

Vous vous demandez peut-être ce que sont devenues du point de vue juridique les recommandations du premier comité sénatorial? Elles ont été suivies dans la mesure où le comité sénatorial ne proposait rien de particulier. L'euthanasie non volontaire demeure toujours une infraction criminelle, tout comme l'euthanasie volontaire; et l'euthanasie non volontaire demeure toujours une infraction au titre des dispositions actuelles du Code criminel sur le meurtre.

Toutefois, les recommandations n'ont pas été suivies dans la mesure où elles devaient être interprétées comme une suggestion de modifier les dispositions sur la détermination de la peine du Code criminel, en vue d'alléger les peines dans les cas où l'euthanasie non volontaire comporte comme élément essentiel le désir de soulager les douleurs de l'autre pour des fins de compassion ou des fins humanitaires. Le Code criminel n'a pas non plus été modifié pour alléger les peines imposées à la suite de



In conclusion, in 1995 the legal status of assisted death in Canada was found to be unclear and indefensible. It remains so today. As the Standing Senate Committee on Euthanasia and Assisted Suicide recognized in "Of Life and Death", both clarification and law reform are needed.

Let us consider, first, the need for clarification. The absence of a clear legislative or judicial statement on the withholding and withdrawal of potentially life-sustaining treatment and the provision of potentially life-shortening palliative treatment identified by the Senate committee remains, and it continues to cause at least six different harms.

First, under the current system, some people are receiving unwanted treatment because their health care providers do not know whether they will be violating the Criminal Code if they do not do everything within their power to sustain life.

Second, patients across the country and even across cities and within institutions are getting significantly different treatment or non-treatment, whether it be the removal of a respirator, provision of massive amounts of morphine or provision of potassium chloride. What they get or do not get depends on the results of the lottery regarding which health care institution they go to or which health care providers they are assigned. Since there is confusion about what the law is, some health care providers will not respect any refusals of potentially life-sustaining treatment. Some will respect refusals of artificial ventilation but not artificial hydration and nutrition; others will respect refusals of any kind of treatment. Some health care providers will respect refusals from competent adults but not from surrogate decision makers. Others will respect refusals from anyone, whether it is the competent adult or an appropriate surrogate. Some health care providers will respect refusals from terminally ill patients but not for patients for whom the prognosis is excellent with the treatment.

Third, some people are not receiving adequate pain control because health care providers do not know whether it is illegal to provide analgesics in doses or ways that will shorten life.

Fourth, health care providers are operating under the shadow of the threat of legal liability. It is easy for me to sit in my office, take a call and say, "No the withholding and withdrawal of life-sustaining treatment is perfectly legal in Canada. The provision of potentially life-shortening treatment is absolutely legal in Canada." I am not at risk of a charge. Even if someone is not at risk of a conviction, realistically they are still at risk or certainly experience being at risk of a charge, and that is a very serious problem. It harms the health care providers because it adds a lot of stress to their lives, and it harms patients because it compromises the care that is provided.

l'euthanasie volontaire incluant comme élément essentiel la compassion.

En conclusion, on déclarait en 1995 que l'aide à la mort avait au Canada un statut juridique imprécis et indéfendable. La situation est la même aujourd'hui encore. Il faut non seulement apporter des précisions à la loi, mais aussi réformer le droit en ce sens, tout comme le réclamait le comité sénatorial spécial sur l'euthanasie et l'aide au suicide dans son rapport, «De la vie et de la mort».

Abordons d'abord la nécessité d'éclaircir la situation. L'absence d'un énoncé législatif ou judiciaire clair sur l'abstention et l'interruption de tout traitement de survie et sur la prestation de traitements palliatifs pouvant éventuellement abréger la vie, reconnue par le comité sénatorial, demeure toujours une priorité, car elle entraîne au moins six préjudices distincts.

D'abord, dans le régime actuel, certains patients reçoivent un traitement qu'ils ne souhaitent pas recevoir parce que les soignants ne savent pas s'ils enfreindront le Code criminel en ne faisant pas tout en leur pouvoir pour garder le patient en vie.

En second lieu, les patients au Canada sont traités très différemment d'une région à l'autre du pays, d'une ville à l'autre, et même d'un établissement à l'autre, qu'il s'agisse de les brancher ou non sur un appareil respiratoire, de leur fournir ou non des quantités massives de morphine ou de chlorure de potassium. Qu'ils soient traités ou non, c'est pour eux comme jouer à la loterie, car cela dépend de l'établissement où ils se trouvent ou du soignant qui s'occupe d'eux. Étant donné que la loi est vague, certains soignants ne respecteront aucun refus de traitement de survie. Certains respecteront le refus du patient d'obtenir de la ventilation artificielle, mais pas le refus de l'hydratation et de l'alimentation artificielles. Certains autres soignants respecteront les refus de traitements qui leur viendront d'adultes capables, mais pas ceux de fondés de pouvoir. D'autres encore respecteront les refus de tous, qu'ils viennent de l'adulte capable ou du fondé de pouvoir. Enfin, certains autres soignants respecteront les refus de traitements de patients en phase terminale, mais pas ceux de patients pour qui le pronostic de rétablissement est excellent s'ils reçoivent le traitement.

En troisième lieu, certains patients ne reçoivent pas de traitements adéquats contre la douleur parce que les soignants ne savent pas s'il est illégal ou pas de fournir des analgésiques à des doses ou sous des formes qui pourraient abréger la vie de leurs patients.

En quatrième lieu, les soignants soignent sous la menace de poursuites pour responsabilité légale. Il est bien facile pour moi de répondre, à partir de mon bureau, que toute abstention ou interruption de traitement de survie est parfaitement légale au Canada et qu'offrir un traitement pouvant abréger la vie est tout aussi légal au Canada, car je ne risque aucune mise en accusation. Celui qui ne risque pas nécessairement d'être déclaré coupable risque néanmoins d'être mis en accusation, ce qui est très sérieux. Cette situation nuit aux soignants, car elle ajoute beaucoup de stress à leur vie déjà remplie et nuit aux patients, car elle compromet les soins qui leur sont offerts.

Fifth, the law is being made on the backs of vulnerable individuals. It is being made on the backs of individuals who have the resources — financial, emotional and physical — to go to court and challenge the system, but those are not the most powerful people in the system. Consider, for example, the burden born by Nancy B. Paralyzed and suffering from Guillain-Barré syndrome, Nancy B. wanted her respirator removed. She had to go to court and, with her family, endure public debate about her right to refuse life-sustaining treatment. She ultimately won the case and, in doing so, helped to establish the right to refuse treatment in Canada. However, she paid a significant personal price. I think leadership should be demonstrated by those with greater resources of all sorts, including legislators, health care professional organizations, and healthy individuals.

The sixth problem is that law is being made on a case-by-case system by the courts, with all of the limits attendant on such a method of making law. The courts are best situated to resolve legal rather than moral issues, whereas the legislators are charged with resolving both morale and legal matters. Furthermore, the courts are constrained by the facts of the case and the abilities and positions of the parties before them, while the legislators, on the other hand, can canvass far more widely and develop general rules.

In 1995, clarification of the legal status of assisted death was needed to stop these harms. It remains needed in 2000.

Consider now the need for reform. First, as has been increasingly clear since 1995, instances of assisted suicide and euthanasia are being treated in an inconsistent fashion. There is a clear lack of a standard response across the country to cases involving assisted suicide and euthanasia. Health care providers in Ontario and Nova Scotia might perform exactly the same acts and yet be tried for murder in Nova Scotia, and be allowed to plead guilty to the administration of a noxious substance in Ontario. This seems manifestly unfair. Law reform was and continues to be necessary to resolve the inconsistent application of the law.

Second, there was and continues to be inconsistency as between the Criminal Code and the administration of justice. Euthanasia is clearly murder, according to the Criminal Code, and yet it is being treated as a lesser crime across the country. Either euthanasia deserves a punishment less than, at least, 25 years in jail, in which case, as was recommended by the Senate committee, the Criminal Code should be amended to reflect that; or it deserves at least 25 years in jail, in which case the pattern of accepting pleas to much lesser charges should be stopped. The current approach of keeping euthanasia under the homicide provisions of the Criminal Code with the mandatory minimum life sentence attached to it, but prosecuting it under the manslaughter or administering a noxious substance provisions is, at best, confusing and, at worst, hypocritical. Law reform was necessary in 1995, and it remains necessary in order to resolve this confusion or hypocrisy.

En cinquième lieu, la loi se fait sur le dos de personnes vulnérables. Elle se fait sur le dos de personnes qui ont les ressources voulues — financières, émotives et physiques — pour contester le système devant les tribunaux, même si ce ne sont pas là les plus puissants. Prenez, par exemple, le fardeau qu'a dû assumer Nancy B., qui était paralysée et qui souffrait du syndrome de Guillain-Barré. Nancy B. voulait qu'on lui retire son respirateur. Pour obtenir cela, elle a dû porter son cas devant les tribunaux et, avec sa famille, endurer tout le débat public qui a entouré son droit de refuser le traitement de survie. Elle a fini par gagner sa cause, et, ce faisant, a aidé à établir le droit au Canada de refuser d'être traité. Toutefois, elle a payé un prix personnel immense. Ceux qui ont plus de ressources de toutes sortes, y compris les législateurs, les organisations des professionnels de la santé, et les individus en santé, devraient faire montre de vision, à mon avis.

Le sixième problème, c'est que le droit évolue en fonction des affaires dont sont saisis les tribunaux, avec toutes les limites que cela implique. Les tribunaux sont mieux en mesure de résoudre les problèmes juridiques que les problèmes moraux, alors que les législateurs sont chargés de résoudre tant les questions morales que les questions juridiques. En outre, les tribunaux sont limités par les faits de l'affaire, la capacité et la position des parties en cause, alors que le législateur, en revanche, peut tenir des consultations plus étendues et élaborer des règles générales.

En 1995, on jugeait nécessaire de préciser si l'aide au suicide était légale afin de mettre fin à ces difficultés. Nous voici en 2000, et cela n'a pas encore été fait.

Pensons maintenant à la nécessité d'une réforme. Tout d'abord, il est de plus en plus manifeste depuis 1995 que les affaires d'aide au suicide et d'euthanasie ne sont pas traitées de façon uniforme. Il n'existe pas de réaction uniforme au Canada aux affaires d'aide au suicide et d'euthanasie. Les dispensateurs de soins de santé de l'Ontario et de la Nouvelle-Écosse peuvent, pour les mêmes actes, être poursuivis pour meurtre en Nouvelle-Écosse ou plaider coupable d'avoir administré un produit dangereux en Ontario. Il semble y avoir là une iniquité patente. Il était et il demeure nécessaire de réformer le droit pour résoudre le manque d'uniformité dans l'application des lois.

Deuxièmement, il existe encore des écarts entre le Code criminel et l'administration de la justice. Dans le Code criminel, l'euthanasie est clairement définie comme un meurtre; et pourtant cet acte est traité au Canada comme un crime de moindre importance. Ou bien l'euthanasie doit entraîner une punition de moins de 25 ans d'emprisonnement, auquel cas il faudrait modifier le Code criminel en conséquence, comme l'avait recommandé le comité du Sénat, ou bien elle mérite un emprisonnement d'au moins 25 ans, auquel cas il faudrait cesser d'accepter des plaidoyers pour réduire les chefs d'accusation. L'approche actuelle, qui consiste à conserver l'euthanasie au rang des homicides dans le Code criminel, à conserver la peine minimale d'emprisonnement à vie qui y est associée, mais à poursuivre les prévenus sous le régime des dispositions relatives à l'homicide involontaire ou à l'administration d'un produit dangereux, est à tout le moins équivoque, sinon hypocrite. Il était



Third, under the current system, we continue to fail the dying, their families and friends and health care providers. For example, people are dying in excruciating pain. People are attempting suicide, failing and ending up in worse shape than before they attempted suicide. People are taking desperate steps to help their patients or loved ones and finding themselves facing the potential of imprisonment for life with no possibility of parole for 25 years. People are refusing life-sustaining treatment for fear of accepting the treatment offered, finding themselves in a situation in which they would feel that life is no longer worth living, but not then being allowed to die.

In 1995, I agreed with the Senate committee finding that the law was in need of both clarification and reform. Unfortunately, I appear before you five years later to say that the law still remains in need of clarification and reform. Therefore, I would argue that the unanimous recommendations made by the Senate committee should be reissued and that persons with the power to implement them should be called upon to do so. They owe it to all Canadians.

**Professor Barney Sneiderman, Faculty of Law, University of Manitoba:** After listening to Ms Downie's excellent overview, I will scrap my opening comments and instead add comments on two cases to which she referred — the Winnipeg *Doerksen* case and the case involving Dr. Morrison. I will mention a number of cases that are relevant.

In 1997, the Manitoba Court of Appeal decided a case called *L. and H.* I will not go into the details of the case. However, should any of you wish further details, I will be glad to give those to you later. The Court of Appeal ruled that a DNR, a "do not resuscitate" order, lies within the exclusive judgement of the attending physician. The court drew a distinction between treatment and non-treatment. According to the court, the only reason that consent is required for treatment is that treatment involves the touching of the patient. The touching of the patient without consent constitutes a battery in civil law and an assault in criminal law. If what is at issue is a DNR order, in essence the patient is not being touched and therefore consent is not required from the patient or a surrogate. It is simply a medical decision.

In the case of *Sawatsky v. Riverview Health Centre*, a Winnipeg case, very briefly, the wife of a debilitated and incompetent 79-year-old patient in an extended care facility objected to a DNR order being placed on his chart. A Queens' Bench judge was persuaded to put the DNR order on hold so that physicians unconnected with Riverview could consider whether it was medically reasonable. The patient was examined by two outside physicians who agreed with the order, but the case did not go back to court because the patient's condition worsened and he died.

nécessaire de réformer le droit en 1995, et ce l'est encore, pour résoudre cette équivoque ou cette hypocrisie.

Troisièmement, dans le régime actuel, nous continuons de manquer à nos devoirs envers les mourants, leurs familles et leurs amis, ainsi qu'envers les dispensateurs des soins de santé. Des gens meurent dans des souffrances intolérables. D'autres essaient de se suicider, manquent leur coup et se retrouvent dans un état pire qu'avant leur tentative. D'autres encore prennent des mesures désespérées pour aider leurs patients ou leurs proches et se trouvent dans des situations qui les rendent passibles d'emprisonnement à vie sans possibilité de libération conditionnelle pendant 25 ans. Certains refusent des traitements de survie par crainte qu'en les acceptant ils ne se retrouvent dans un état où la vie n'en vaut plus la peine et qu'il ne leur soit interdit de mourir.

En 1995, j'étais d'accord avec la conclusion du comité du Sénat, selon qui il était nécessaire de préciser et de réformer le droit. Cinq ans plus tard, je dois malheureusement vous dire qu'il est toujours nécessaire de préciser et de réformer le droit. Je soumets donc que les recommandations unanimes du comité du Sénat devraient être réitérées et qu'il faudrait exhorter les personnes qui ont le pouvoir de les mettre en oeuvre à le faire. C'est leur devoir envers tous les Canadiens.

**M. Barney Sneiderman, professeur faculté de droit, Université du Manitoba:** Après l'excellent tour d'horizon de Mme Downie, je m'abstiendrai de lire mes observations préliminaires et je me contenterai d'ajouter des commentaires aux deux affaires qu'elle a mentionnées — l'affaire *Doerksen* de Winnipeg et l'affaire dans laquelle était impliqué la docteure Morrison. Je mentionnerai toutefois un certain nombre d'autres affaires pertinentes.

En 1997, la Cour d'appel du Manitoba a rendu une décision dans l'affaire intitulée *L. et H.* Je n'entrerai pas dans les détails de cette affaire. Si cela vous intéresse, je pourrai vous en dire davantage plus tard. La Cour d'appel a décidé que seul le médecin traitant peut décider d'exécuter une ordonnance de non-réanimation. La cour a établi une distinction entre le traitement et le non-traitement. D'après les juges, la seule raison pour laquelle il est nécessaire d'obtenir le consentement au traitement, c'est que pour traiter le patient il faut le toucher. Toucher le patient sans son consentement est un acte défini comme «coups et blessures» en droit civil et comme «voies de fait» en droit pénal. Dans le cas d'une ordonnance de non-réanimation, on ne touche pas le patient, et il n'est donc pas nécessaire de ce fait d'obtenir le consentement du patient ou de son fondé de pouvoir. C'est une simple décision médicale.

Je veux décrire très brièvement l'affaire *Sawatsky c. Riverview Health Centre*, de Winnipeg. Un patient débilité et incapable de 79 ans était soigné dans un établissement de soins de longue durée. Sa femme s'est opposée à ce qu'une ordonnance de non-réanimation soit déposée dans son dossier. On a réussi à persuader un juge du Banc de la Reine de surseoir à l'ordonnance de façon à ce que des médecins de l'extérieur du centre de Riverview puissent examiner si l'ordonnance était raisonnable du point de vue médical. Le patient a été examiné par deux médecins indépendants qui se sont dits d'accord avec l'ordonnance.

The *Sawatsky* case involved an insistence upon treatment which the law has yet to recognize. The question it raises is whether the law's recognition of the negative right to refuse treatment should be extended to include a positive right by patient or family to enforce a demand for treatment that the physician regards as medically unreasonable, as offering no potential benefit to the patient.

There is also the question of when treatment is medically reasonable, which of course takes us into the incredibly complex realm of medical futility. What makes the futility issue even more complex is the failure to keep it separate from the issue of the rationing of health care.

The *Sawatsky* case highlights the public concern with both overtreatment and undertreatment. On the one hand, there is the spectre of medical technology that prolongs the dying process to no rationale end, a spectre which explains the development of health care directives. On the other hand, there is the legitimate fear of undertreatment by our beleaguered and much maligned health care system. Much of the media coverage of the *Sawatsky* case portrayed it as a David and Goliath encounter — a elderly and devoted wife single-handedly seeking to save her husband from the clutches of an impersonal medical system. For example, one front page article in *The Globe and Mail* was headlined "Doctors won't save man despite wife's plea." In letters to the press and comments on radio talk shows, concerned Manitobans expressed agreement with Mrs. Sawatsky when she said about her husband, "They have written him off. The older you get, the more vulnerable you become, the more expendable you get."

I am certainly not suggesting that we must always prolong patients' lives. I for one believe that the DNR order in the *Sawatsky* case was right. However difficult if not impossible it is to define "futility" as a matter of general policy, scores of patients die every day in Canadian hospitals because physicians and families reasonably agree that the dying process should not be prolonged simply because the medical technology is there.

Medical futility is the kind of rationale that, in a different era, could lead us into an Orwellian nightmare. I refer to medical futility in the medical context as the troublesome "F word" — troublesome indeed.

I would like to shift gears now. When the committee's report was issued in 1995, it revealed a decided lack of consensus regarding the legalization of euthanasia and assisted suicide. However, there was an issue that produced unanimity; that being that mercy killing should be recognized as a reduced category of culpable homicide for which there would be no mandatory minimum sentence. Parliament may have heard the message, but

Toutefois, la cour n'a pas été saisie de nouveau de l'affaire parce que l'état du patient s'est empiré et qu'il est mort.

Dans l'affaire *Sawatsky*, il s'agissait d'une insistance pour obtenir le traitement, cas que le droit n'a pas encore reconnu. Ce qu'il faut déterminer, c'est si la reconnaissance en droit du refus du traitement devrait comprendre également le droit inverse, c'est-à-dire le droit du patient ou de sa famille d'exiger le traitement, même si le médecin estime que ce n'est pas raisonnable du point de vue médical et que le traitement ne présente aucun avantage pour le patient.

Il faut également déterminer quand le traitement est raisonnable du point de vue médical, ce qui nous entraîne dans le chapitre fort complexe de l'acharnement médical. Ce qui rend la question de l'acharnement médical encore plus complexe, c'est qu'il est impossible de la tenir à l'écart de la question du rationnement des soins de santé.

L'affaire *Sawatsky* signale l'inquiétude du public envers le traitement excessif et le manque de traitement. D'une part, il existe la possibilité que la technologie médicale prolonge l'agonie de façon injustifiée; cette inquiétude explique la création des directives en matière de soins de santé. Par contre, il existe une crainte légitime que des traitements nécessaires ne soient pas offerts par notre régime de soins de santé assiégé et tant décrié. Pour la plupart, les journalistes ont dépeint l'affaire *Sawatsky* comme un combat entre David et Goliath — celui d'une épouse âgée et dévouée qui essayait de tirer son mari des griffes d'un système médical dépersonnalisé. Par exemple, on pouvait lire en première page du *Globe and Mail* le titre suivant: «Les médecins ne sauveront pas le patient en dépit des exhortations de son épouse.» Dans leurs lettres aux journaux et leurs commentaires aux tribunes radiophoniques, des Manitobains inquiets se sont dits d'accord avec Mme Sawatsky lorsqu'elle affirmait, au sujet de son mari: «Ils l'ont abandonné. Plus on vieillit, plus on devient vulnérable et plus on devient inutile.»

Je ne dis certes pas qu'il faut toujours prolonger la vie des patients. Je suis de ceux qui estimaient justifiée l'ordonnance de non-réanimation dans l'affaire *Sawatsky*. Même s'il est difficile, sinon impossible, de définir ce qu'est l'acharnement thérapeutique dans le contexte d'une politique générale, il n'en reste pas moins qu'un grand nombre de patients meurent chaque jour dans les hôpitaux canadiens parce que leurs médecins et les membres de leurs familles reconnaissent que l'agonie ne devrait pas être prolongée du simple fait de l'existence de la technologie médicale.

L'acharnement thérapeutique pourrait, dans une autre ère, nous entraîner dans un cauchemar orwellien. Dans le contexte médical, il s'agit pour moi d'acharnement avec un A majuscule — un grand sujet d'inquiétude.

Permettez-moi maintenant de passer à autre chose. Le rapport du comité, publié en 1995, révélait un manque certain de consensus sur la légalisation de l'euthanasie et de l'aide au suicide. Il y avait toutefois unanimité sur une question: l'euthanasie devrait être considérée comme un homicide coupable réduit et ne devrait pas entraîner de peine minimum obligatoire. Le message s'est peut-être rendu jusqu'au Parlement, mais au



in the nearly five years since it was delivered there is nothing to indicate an inclination to act upon it.

Sometime later this year, the Supreme Court will hear the appeal of Robert Latimer from his mandatory minimum sentence, life imprisonment with no eligibility for parole for 10 years. Disability groups have been granted intervenor status and will no doubt present impassioned arguments that the sentence be upheld. I acknowledge the anxiety and outrage that has emerged from within the disabled community at the killing of Tracey Latimer. By the "disabled community" I mean the disabled themselves and caregivers of the disabled.

I do not believe that Robert Latimer is their enemy. If he had devalued his daughter's inherent worth as a human being, then surely he would not have provided her with 12 years of loving care and devotion. From those who damn him bitterly, he gets no credit for not taking the easy way out and institutionalizing her, and no credit for all the years of incredible patience, ceaseless toil, and heartbreak that he and his wife endured for the sake of their daughter.

There is an aspect of the *Latimer* case which has been ignored. The 12 ordinary citizens who conscientiously fulfilled their civic duty as the jurors in his 1997 trial convicted Latimer for the killing of his disabled daughter Tracey. After all, he had no legally recognized defence and this was a conscientious jury. However, after returning their verdict, they were appalled to learn from the trial judge that the least time he could serve was 10 years.

As you know, the jury defiantly and unanimously recommended that Latimer serve but one year. The trial judge, Justice Noble, responded with a two-year sentence, but only one year in custody. As Professor Downie has informed you, that decision was overturned by the Saskatchewan Court of Appeal and the 10-year sentence instituted.

The jurors were able to take the measure of the man. They were there, they attended the trial, they heard all the evidence, and they concluded that 10 years was way out of line. Having the collective sense that this was a murder case calling for leniency, they, in effect, came to the same consensus as did this committee: that a true mercy killing is no ordinary murder. Given how distraught they were when they heard of the 10-year minimum, they presumably, but mistakenly, had assumed that the law was sufficiently enlightened to allow for a sentence reflecting the facts of the case.

If the sentence is upheld by the Supreme Court, how are they going to look back over the years at their jury experience? With bitterness and outrage, I would image.

The law puts the fate of a man in their hands but refuses to tell them what a guilty verdict can mean. In reversing Justice Noble's sentence, the Court of Appeal gave short shrift to the jury's recommendation, in effect telling the jurors, "Butt out. This is none of your business." That, after all, is the conventional wisdom. The jury's role was simply to decide guilt or innocence, and therefore the crime but not the punishment is their proper

cours des cinq années ou presque qui se sont écoulées il n'a donné aucun indice de sa volonté d'agir dans ce sens.

Un peu plus tard cette année, la Cour suprême entendra l'appel de Robert Latimer au sujet de sa peine minimum obligatoire, c'est-à-dire l'emprisonnement à vie sans possibilité de libération conditionnelle pendant 10 ans. On a donné qualité d'intervenant à des groupes de personnes handicapées qui plaideront sans doute de façon passionnée pour que la sentence soit maintenue. Je sais que le meurtre de Tracey Latimer a soulevé beaucoup d'angoisse et d'indignation chez les personnes handicapées. Quand je parle des «personnes handicapées», j'entends par là les personnes handicapées elles-mêmes et celles qui leur dispensent des soins.

Je ne crois pas que Robert Latimer soit leur ennemi. S'il n'avait pas été convaincu de la valeur inhérente de sa fille en tant qu'être humain, il ne lui aurait certes pas consacré 12 ans de soins attentifs et de dévouement. Ceux qui le condamnent amèrement ne reconnaissent pas son mérite de ne pas avoir opté pour la facilité, de ne pas avoir placé sa fille en établissement, non plus que son mérite et celui de sa femme d'avoir enduré pour leur fille toutes ces années de patience incroyable, de travail incessant et de peine.

L'affaire *Latimer* a un aspect dont on n'a pas tenu compte. Les 12 citoyens moyens qui ont rempli consciencieusement leur devoir à titre de jurés dans le procès de 1997 ont condamné Latimer du meurtre de sa fille handicapée, Tracey. Après tout, il n'a présenté aucune défense reconnue par les tribunaux, et le jury était consciencieux. Toutefois, après avoir rendu leur verdict, ces citoyens ont été horrifiés d'entendre le juge décréter que la peine minimale d'emprisonnement serait de 10 ans.

Comme vous le savez, le jury a courageusement et unanimement recommandé que Latimer ne purge qu'une année d'incarcération. Le juge au procès, le juge Noble, a réagi en imposant une peine de deux ans, dont un an seulement en prison. Comme Mme Downie vous l'a dit, la Cour d'appel de la Saskatchewan a renversé cette décision et imposé la peine minimale de 10 ans.

Les jurés ont pu juger de l'homme. Ils étaient sur place, au procès, ils ont entendu tous les témoignages et ont conclu qu'une peine de 10 ans était exagérée. Ils estimaient collectivement que dans ce cas le meurtre pouvait être traité de façon plus clément et en sont arrivés à la même conclusion que votre comité, c'est-à-dire que l'euthanasie n'est pas un meurtre ordinaire. Si leur désarroi a été aussi grand, au prononcé d'une peine minimale de 10 ans, c'est qu'ils avaient présumé, peut-être à tort, que le droit était suffisamment éclairé pour que la peine soit proportionnelle à l'affaire.

Si la Cour suprême maintient la peine, que penseront-ils plus tard de leur expérience de juré? Ils ressentiront de l'amertume et un sentiment d'indignation, je suppose.

Le droit place entre leurs mains le sort d'un homme, mais refuse de leur dire quel sera le résultat d'un verdict de culpabilité. La Cour d'appel n'a pas tenu compte de la recommandation du jury lorsqu'elle a renversé la peine imposée par le juge Noble. Dans les faits, elle a dit aux jurés de se mêler de leurs affaires. Après tout, n'est-ce pas ainsi que les choses se passent habituellement? Le rôle du jury est simplement de décider de la

concern. That is well and good when the crime before the jury carries a wide sentencing range and no mandatory prison term, but murder is different. According to the law, the only victim in the *Latimer* case is Tracey Latimer. In one sense, the jurors are victims too. Juries are supposed to express the sense of the community, and when these jurors did that, when they sent a signal that the law ignored, they were left with the burden of knowing that their verdict paved the way for a punishment they believe is way out of line. What kind of message does that send to every citizen who may be called upon one day to do jury duty?

There are as well the other victims; Laura Latimer and the three Latimer children. Only days after the verdict, but before Justice Noble's remarkable sentence, three of the jurors expressed their dismay at the spectre of a 10-year sentence in a CBC interview, and two spoke about Latimer's family. One said, "He has children at home; young children that need him." Another said, "It's not going to do him any good to be in jail, nor his family. I think he would be better off being at home where he could take care of his family."

There are those who interpret Justice Noble's sentence to mean that killing the disabled is a lesser crime than killing the non-disabled, but that was not his message. As he took pains to emphasize, the evidence clearly established that Latimer ended his daughter's life because he knew no other way to end the pain that marked her life and that tore at his heart; and not because he regarded her as a lesser human being. The sentencing principle of denunciation has its place, but not in this kind of case. Those who insist that this message be sent, however misdirected it is in this case, should know that it will wreak havoc upon this family, and do not forget that it is Tracey's family to which I refer.

That family has undergone the most incredible stress since Tracey's death in 1993, and the three siblings have really known no other life other than one pervaded by the dread of losing their father. If they are not already permanently scarred victims, then surely they will be if the 10-year minimum sentence is upheld.

In my view, that sentence is so grossly disproportionate to the offence as to cry out for relief, particularly in light of less severe maximum sentences that can apply to the most horrific offenders committing the most heinous offences short of murder. When the Latimer jury called for a one-year sentence, it was, in effect, exhibiting an intuitive grasp of cruel and unusual punishment; that it is not enough that the punishment fit the crime, but that it also fit the criminal. A sizeable majority of Canadians apparently feel the same because, according to a recent Angus Reid poll, by a margin of 73 to 23 per cent, respondents supported the proposition that Latimer "acted out of compassion and should receive a more lenient sentence."

Five years later, there is absolutely no indication that Parliament is prepared to act upon the committee's mercy killing proposal. In any case, I believe it is evident that a mercy killing

culpabilité ou de l'innocence; il s'occupe du crime, mais non du châtiment. C'est bien beau lorsque le crime dont est saisi le jury entraîne un vaste choix de sanctions et aucune incarcération obligatoire; mais ce n'est pas le cas du meurtre. D'après la loi, seule Tracey Latimer a été une victime dans cette affaire. On pourrait croire également que les jurés ont aussi été des victimes. Les jurés sont censés exprimer le sentiment de la société; lorsqu'ils l'ont fait, ils ont lancé un message dont le droit n'a pas tenu compte, et leur conscience est maintenant alourdie de savoir que leur verdict a entraîné un châtiment qu'ils estiment exagéré. Quel message cela donne-t-il à tous les citoyens qui pourraient être un jour appelés à être jurés?

Il y a également d'autres victimes: Laura Latimer et ses trois enfants. Quelques jours seulement après le verdict, mais avant le prononcé remarquable de la peine par le juge Noble, trois des jurés interviewés par la SRC ont exprimé leur désarroi à l'idée d'une peine de 10 ans. Deux d'entre eux ont parlé de la famille de Latimer. L'un a dit: «Il a chez lui de jeunes enfants qui ont besoin de lui.» L'autre a dit: «Son incarcération ne sera utile ni à lui ni à sa famille. Il vaudrait mieux qu'il soit chez lui, à prendre soin de sa famille.»

Certains interprètent la peine imposée par le juge Noble comme un indice de ce que tuer une personne handicapée est un acte criminel moins grave que le meurtre d'une personne non handicapée. Ce n'était pas son message. Il a pris la peine d'expliquer que d'après les preuves il était clair que Latimer a mis fin à la vie de sa fille parce qu'il ne connaissait aucun autre moyen de mettre fin à sa souffrance à elle et à sa peine à lui; il ne l'a pas fait parce qu'il la considérait comme un être humain moins important. Le principe de la dénonciation doit être pris en compte dans l'établissement de la peine, mais pas dans un cas de ce genre. Ceux qui insistent sur ce message, aussi mal adressé qu'il soit dans ce cas-ci, devraient savoir qu'il bouleverse cette famille; et n'oubliez pas que c'est de la famille de Tracey que je parle.

Depuis la mort de Tracey, en 1993, cette famille a vécu dans le stress le plus incroyable; les trois autres enfants ont vécu toute leur vie dans la crainte de perdre leur père. S'ils ne sont pas déjà marqués à vie, ils le seront sûrement si la peine minimale de 10 ans est maintenue.

À mon avis, cette peine est si disproportionnée par rapport au crime qu'elle réclame un allègement, surtout compte tenu des peines maximales moins importantes qu'on peut imposer aux criminels les plus endurcis qui commettent les crimes les plus haineux, abstraction faite du meurtre. En réclamant une peine d'un an, le jury manifestait, en fait, sa compréhension intuitive du concept de la peine cruelle et inhabituelle. Il disait qu'il n'est pas suffisant de châtier le crime, que le châtiment doit également correspondre au criminel. Une majorité appréciable de Canadiens partageaient ce sentiment, apparemment, puisque, d'après un récent sondage Angus Reid, 73 p. 100 des répondants ont appuyé l'affirmation voulant que Latimer avait agi par compassion et devrait se voir imposer une peine plus clément, comparativement à 23 p. 100 contre.

Cinq ans plus tard, le Parlement n'a donné aucun indice de son intention d'adopter la proposition du comité au sujet de l'euthanasie. De toute façon, j'estime qu'il est évident qu'un



bill would be greeted by a public storm of protest and heated rhetoric that would make calm and reasoned discussion very difficult.

I have learned from personal experience that, if you advocate a mercy killing defence to an audience that contains members of the disabled community, you will be met with an outraged response that compares your viewpoint to the Nazi euthanasia program, as an invitation to the mass murder of the disabled by their caregivers who would, supposedly, find sympathetic jurors who would likewise devalue the lives of the disabled by all too eagerly embracing a mercy killing defence. You will hear that there is no such thing as a mercy killing; that it is nothing more than the killing of a disabled dependent to suit the convenience of the caregiver.

Of course, we keep hearing that the disabled community is against leniency for Robert Latimer. However, I have three disabled friends who feel as I do about his case. Therefore, what we are hearing is not necessarily the voice of the disabled. Why should that community speak with one voice on a issue any more than any other community would likely speak with one voice on an issue? All we know is that what we are hearing is the voice of some of those who hold themselves out as speaking for that community. Of course, I do not mean to imply that opposition to leniency for Robert Latimer comes only from the disabled community, but it is the disabled community which has produced his most vocal and impassioned critics.

Ms Downie referred to the *Doerksen* case, a case with which I am quite familiar. It is an assisted suicide case. If you were the defence lawyer, you could not ask for a better case. At the time of his wife's death two years ago, Bert Doerksen was 79 years old. His wife was 78 years old. She was suffering from a number of serious illnesses, including intractable pain, with which the Winnipeg pain clinic was simply unable to deal. She had been taking narcotics for so many years that they proved ineffective. The Doerksens had been married for 59 years. They had been dating for three years before that as teenagers. They got together when he was 17 and she was 16. Sixty-two years later, she died in the family garage from carbon monoxide poisoning and he is charged with assisted suicide. I have met Bert Doerksen who is a remarkable and extremely intelligent man. He has not been the same since his wife's death — he misses her terribly. He has cancer of the bone marrow and of the esophagus. The Crown said that if he were to plead guilty he would not be jailed. Bert Doerksen refuses to plead guilty. He says he was born clean and plans to leave this life clean. I suspect he will not plead guilty because that would involve an admission that he had done wrong, something which he is not prepared to accept.

According to the attorney general's department, there has been vocal opposition expressed to the dropping of the charge against Bert Doerksen. That opposition has come from the disabled community. The Crown refuses to drop the charge.

projet de loi sur l'euthanasie soulèverait un tollé de protestations chez le public et des discours passionnés qui rendraient très difficile un débat calme et raisonné.

Mon expérience personnelle m'a montré que si vous défendez l'euthanasie devant un auditoire qui contient des personnes handicapées, vous soulèverez un sentiment d'indignation, et votre opinion sera comparée au programme nazi d'euthanasie, à une invitation au meurtre en masse des personnes handicapées par leurs dispensateurs de soins qui, soi-disant, trouveront des jurés sympathiques à leur cause et prêts à minimiser la valeur de la vie des handicapés en appuyant avidement une défense pour euthanasie. On vous dira qu'il ne s'agit pas d'euthanasie, mais bien du meurtre d'une personne à charge handicapée, pour accommoder le dispensateur de soins.

Évidemment, on nous dit toujours que les handicapés s'opposent à la clémence envers Robert Latimer. J'ai toutefois trois amis handicapés qui sont du même avis que moi dans cette affaire. Par conséquent, ce que nous entendons, ce n'est pas nécessairement l'opinion des personnes handicapées. Pourquoi celles-ci n'auraient-elles qu'une seule opinion sur un sujet alors qu'il existe probablement des opinions diverses dans tous les autres groupes? Tout ce que nous savons, c'est que ce que nous entendons, c'est l'avis de ceux qui se prétendent les porte-parole de cette communauté. Je ne dis pas non plus que seules les personnes handicapées s'opposent à la clémence pour Robert Latimer, mais c'est néanmoins de cette communauté que sont issues ses critiques les plus passionnés et les plus virulents.

Mme Downie a parlé de l'affaire *Doerksen*, que je connais très bien. Il s'agit d'une affaire d'aide au suicide. Pour un avocat de la défense, c'est une affaire en or. Lorsque sa femme est décédée, il y a deux ans, Bert Doerksen avait 79 ans et sa femme, 78. Elle souffrait d'un certain nombre de maladies graves, entre autres de douleurs incurables, que la clinique de soins palliatifs de Winnipeg était incapable de soulager. Elle prenait des narcotiques depuis tant d'années qu'ils ne faisaient plus aucun effet. Les Doerksen étaient mariés depuis 59 ans. Ils s'étaient fréquentés pendant trois ans, alors qu'ils n'étaient qu'adolescents. Lorsqu'ils se sont mariés, il avait 17 ans et elle en avait 16. Soixante-deux ans plus tard, elle mourait dans le garage de la famille d'un empoisonnement au monoxyde de carbone, et il était accusé de l'avoir aidée à se suicider. J'ai rencontré Bert Doerksen, qui est un homme remarquable et extrêmement intelligent. Il n'est plus le même depuis la mort de sa femme — elle lui manque terriblement. Il souffre d'un cancer de la moelle osseuse et de l'oesophage. Le procureur de la Couronne a déclaré que s'il plaiderait coupable il ne serait pas incarcéré. Bert Doerksen refuse de plaider coupable. Il dit qu'il est né avec une conscience nette et qu'il prévoit mourir de la même façon. Je soupçonne que s'il refuse de plaider coupable, c'est parce qu'il devrait admettre qu'il a commis un acte mauvais et qu'il n'est pas prêt à l'accepter.

D'après le ministère du Procureur général, des protestations se seraient élevées contre le retrait de l'accusation contre Bert Doerksen. Ces protestations viendraient d'handicapés. La Couronne refuse de retirer cette accusation.

I wrote an op-ed piece for the *Winnipeg Free Press* a few months ago in which I quoted from the prosecution's guidelines regarding when it is appropriate to stay proceedings in a case. I pointed out that about six of their eight criteria fit the *Doerksen* case. They will not drop the charge.

I have heard that the Crown is hoping that he will die from cancer. That will alleviate the Crown from the spectacle of putting Bert Doerksen on trial.

I have said that it is my view that the committee's mercy killing proposal has scant chance of enactment. There is another avenue of approach, that is, a modification of the mandatory minimum sentencing for murder by a presumptive sentencing scheme such as was argued for in a recent article published in the *Alberta Law Review* about the *Latimer* case. The argument is to keep the mandatory minimums but amend the Criminal Code to allow an accused the opportunity to prove, by compelling evidence, why the minimum should be waived in his case. Therein lies a way to mitigate the rigidity of the law for a true mercy killing case.

There is really much that we could do if we were to have some way to get around the ironclad rule that conviction for murder requires a mandatory minimum sentence of 10 years. There are groups lobbying for the repeal of the defence of provocation for a charge of murder. If that happens, I predict a jury will acquit in a case where there should be a conviction, or a jury will convict and then there will be an uproar that the 10-year sentence is too harsh. If we had something like a presumptive sentencing scheme in effect, then we could abolish the provocation defence. Certainly, from the standpoint of an accused, it is not the label that attaches to the crime, it is the sentence.

In the area of the battered woman syndrome and self-defence it is the same thing. There might be a case where we say, "Well, this is really not self-defence. Technically, it does not fit within the parameters of provocation. However, if we had some way around the mandatory minimum sentence, then we could reach some kind of acceptable result."

**Senator Beaudoin:** You said that there has been no amendment to the Criminal Code since our report was made. I would point out that there has been, here and there. As it relates to the Criminal Code, I have always thought that we should at least implement that part of our report on which we were all unanimous. That dealt mostly with palliative care, the withdrawal of life support and the withholding of treatment. I have no problem with that. We have a serious job to do in this field.

When a matter involves amendments to the Criminal Code there is no problem because we have full jurisdiction. However, palliative care falls partly within provincial jurisdiction and partly within federal jurisdiction. In many cases, it falls entirely under provincial jurisdiction. Nonetheless, there is such a thing as the evolution of jurisprudence. It is true that the Criminal Code has

J'ai écrit un article paru en regard de la page éditoriale du *Winnipeg Free Press* il y a quelques mois dans lequel je citais les lignes directrices en matière de poursuites au sujet des conditions de sursis de procédure. Je signalais qu'environ six des huit critères s'appliquaient à la cause Doerksen. On ne veut pas retirer l'accusation.

J'ai entendu dire que la Couronne espère qu'il va mourir du cancer. Cela lui éviterait de lui faire subir un procès.

J'ai dit que je ne crois pas que la proposition du comité concernant le meurtre par compassion ait de grandes chances d'être adoptée. Il y a une autre façon de procéder, qui serait de modifier la détermination de la peine minimum obligatoire pour meurtre par un système de détermination de la peine par présomption tel que proposé dans un article récent publié dans le *Alberta Law Review* à propos de la cause *Latimer*. L'idée est de maintenir des minimums obligatoires, mais de modifier le Code criminel pour permettre à un accusé de prouver, par preuve péremptoire, pourquoi il devrait être relevé de cette peine minimum. Ce serait la façon d'atténuer la rigidité de la loi pour un véritable cas de meurtre par compassion.

Nous pourrions en fait faire beaucoup si nous avions une façon de contourner la règle stricte selon laquelle une condamnation pour meurtre entraîne automatiquement une peine minimum obligatoire de 10 ans. Il y a des groupes qui préconisent l'abrogation du motif de défense de provocation pour une accusation de meurtre. S'il était abrogé, je prédis qu'un jury acquittera un prévenu qui devrait être condamné ou qu'un jury condamnera et que cela suscitera de grandes protestations contre la sévérité d'une peine de 10 ans. Si nous avions quelque chose comme un système de détermination de la peine par présomption, nous pourrions alors abolir la défense de provocation. Certes, du point de vue d'un accusé, ce qui importe, n'est pas l'étiquette que l'on donne au crime, c'est la peine.

Dans le domaine du syndrome de la femme battue et de l'autodéfense, c'est la même chose. On pourrait peut-être dire: «Ma foi, il ne s'agit vraiment pas d'autodéfense. Cela ne correspond pas aux paramètres de la provocation. Toutefois, si nous avions un moyen de contourner la peine minimum obligatoire, nous pourrions parvenir à un résultat plus acceptable.»

**Le sénateur Beaudoin:** Vous dites que l'on n'a pas modifié le Code criminel depuis notre rapport. Je vous signalerai qu'il y a toutefois eu certaines modifications. Pour ce qui est du Code criminel, j'ai toujours pensé que nous devrions au moins mettre en oeuvre la partie de notre rapport sur laquelle nous étions tous unanimes. Il s'agissait essentiellement des soins palliatifs, de l'interruption du maintien des fonctions vitales et du refus de traitement. Je n'y verrais pas d'inconvénient. Nous avons beaucoup à faire dans ce domaine.

Lorsqu'une question entraîne des amendements au Code criminel, il n'y a pas de problème, parce que nous avons toute compétence en la matière. Toutefois, les soins palliatifs relèvent en partie de la compétence provinciale. Dans bien des cas, cela relève entièrement de la compétence provinciale. Néanmoins, il y a l'évolution de la jurisprudence. Il est vrai que le Code criminel



not been amended, but there have been certain cases which may change the law through the interpretation of the law. Are these landmark cases which will cause amendments to be made to the Criminal Code?

**Ms Downie:** With respect to the area of assisted death on which there were unanimous recommendations, particularly withholding, withdrawal and potentially life-shortening palliative treatment, the most significant case was *Rodriguez* which was a case of assisted suicide. It had some important passages about withholding, withdrawal and life-shortening palliative treatment. That came out before the report came out. Thus, the legal status did not change from the time of the report because of *Rodriguez*. Perhaps not a great enough awareness of what is buried inside *Rodriguez* has come out because the case does say that, clearly, competent adults have the right to refuse life-sustaining treatment no matter what. It says that there is a difference between the ever-escalating levels of morphine and an injection of potassium chloride. It is a very important case for those points. However, the problem is that it was an assisted suicide case; it was not about withholding treatment or withdrawal of life support. It does not touch the remaining grey areas of withholding and withdrawal.

You could argue that you do not need to have the legislation around withholding and withdrawal because of a certain passage in *Rodriguez*. I would take exception to that because you want a clear statement and not some passage buried in a case that is not about withholding or withdrawal. Most doctors do not know about this paragraph buried in *Rodriguez*.

More important, there are other aspects of withholding and withdrawal upon which the case does not touch in the least, and that is why we need legislation. We do not have cases to make the clear point about mature minors who are refusing treatment, or those who demand treatment rather than refuse it, or incompetent adults without advance directives. Those are not touched by *Rodriguez* or in a convincing way by any of the cases we have seen. The cases subsequent to *Rodriguez* are low level. We either need some clear legislation or we need the court to rule on a range of these cases.

Those are the two avenues we have for getting clarity on the legal status of the range of issues that arise in the context of withholding, withdrawal and potentially life-shortening palliative treatment.

**Senator Beaudoin:** I agree with you that we need to amend the Criminal Code. With respect to the withdrawal and the withholding of treatment, the jurisprudence is perhaps unclear and we need some amendments to the Criminal Code. This would benefit the families, the doctors, the nurses, et cetera.

As you said, the *Rodriguez* case dealt mainly with assisted suicide and did not touch on withholding or withdrawing treatment. It certainly was not part of the decision.

**Ms Downie:** It was *obiter*.

n'a pas été modifié, mais il y a certaines causes qui peuvent changer la loi de la façon dont elle est interprétée. S'agit-il de causes repères qui mèneront à modifier le Code criminel?

**Mme Downie:** Pour ce qui est de l'aide à la mort et des recommandations unanimes, en particulier pour ce qui est du refus, de l'interruption et du traitement palliatif risquant de raccourcir la vie, la cause la plus importante fut la cause *Rodriguez* un cas de suicide assisté. Cela comportait des passages importants sur le refus, l'interruption et le traitement palliatif qui abrège la vie. C'est sorti avant le rapport. Aussi, la loi n'a-t-elle pas changé depuis le rapport du fait de *Rodriguez*. Peut-être que l'on n'a pas été suffisamment sensibilisé à ce que comportait *Rodriguez*, parce qu'il est dit clairement que des adultes compétents ont le droit de refuser un traitement par maintien des fonctions vitales, quel qu'il soit. On déclare qu'il y a une différence entre l'augmentation constante des doses de morphine et une injection de chlorure de potassium. C'est une cause très importante pour cela. Toutefois, le problème est qu'il s'agissait d'un cas d'aide au suicide; il ne s'agissait pas de refuser un traitement ni d'interrompre le maintien des fonctions vitales. Cela ne touche pas aux autres zones grises du refus et de l'interruption.

On peut dire que l'on n'a pas besoin de loi à propos du refus et de l'interruption, car voilà ce qu'il faut dans un certain passage de la décision concernant *Rodriguez*. Je ne suis pas d'accord, parce qu'il faut quelque chose de clair, et non pas un passage obscur enterré dans une décision qui ne porte pas sur le refus ou l'interruption. La majorité des médecins ne sont pas au courant de ce paragraphe enfoui dans la décision *Rodriguez*.

Surtout, il y a d'autres aspects du refus et l'interruption que cette cause ne touche absolument pas, et c'est pourquoi il nous faut un texte législatif. Nous n'avons pas de causes nous permettant d'énoncer clairement les choses en ce qui concerne les mineurs mûrs qui refusent un traitement ou ceux qui en exigent un plutôt que de le refuser, ou des adultes incapables de décision sans directives préalables. Il n'en est pas question dans *Rodriguez* ni de façon convaincante dans l'une des autres causes que nous avons vues. Après *Rodriguez*, les causes sont moins importantes. Il nous faut soit un texte législatif clair, soit une décision de la cour sur une série de cas semblables.

Voilà les deux voies qui s'offrent à nous pour obtenir la clarté voulue sur la légalité de toute la série de questions qui se posent dans le contexte du refus, de l'interruption ou de traitements palliatifs pouvant abrégier la vie.

**Le sénateur Beaudoin:** Je suis bien d'accord avec vous pour dire qu'il nous faut modifier le Code criminel. Pour ce qui est de l'interruption et du refus de traitement, la jurisprudence n'est peut-être pas assez claire, et il nous faut envisager certains amendements au Code criminel. Cela servirait les familles, les médecins, le personnel infirmier, et cetera.

Comme vous le disiez, la cause *Rodriguez* traitait essentiellement du suicide assisté et non pas du refus ou de l'interruption. Cela n'entrait certainement pas dans la décision.

**Mme Downie:** C'était une observation incidente.

**Senator Beaudoin:** It was a five-to-four decision. We consider that the *Rodriguez* case is clear in respect of assisted suicide, and that is all we say, not more, not less. In respect of the other two issues, withdrawal and withholding, we have a lot to do.

I would like to know if you do or do not consider that the jurisprudence has shed any light on this issue, because you have analyzed a number of cases since 1995, and obviously any information you can give us may throw some light on the decision that we must make.

**Ms Downie:** Let us take a couple of examples of the pockets of grey area within withholding and withdrawal, and consider the cases which touch on those issues. One example is related to mature minors. That is left unclear, as you yourself recognized. As you noted before, the jurisdiction rests with the provinces, and so what we have is some provincial legislation that has made it clear that minors' refusals of treatment should be respected, but there is some confusion in the legislation. Sometimes they say it is any refusal, as long as the minor is competent, as competent as an adult; and others say it is if he or she is competent and is making the decision in his or her best interests.

There is similar confusion in the case law. We have, for instance, two cases out of B.C. that are important here. In one, the judge says that if you are a minor but you understand the nature and the consequences of the decision to be made, your refusal should be respected, except the court always has *parens patriae* jurisdiction, which means the court can step in if believes the minor is making a bad decision. That case says it is a limited mature minor rule. Another decision came from the Court of Appeal a short while later. One judge in that case said it is an unlimited mature minor rule, that you cannot have a best-interest tag — it does not apply to adults so it should not apply to competent minors. Another judge in that same case, though, said, no, we retain that limit so that, a minor must be not only competent but making a decision that is in his or her best interests.

I would suggest that, in the context of mature minors, the case law does not resolve the issue for us at all. If anything, it muddies it. At least the issue has been considered, which was not what we had in the past, but we have no clear answer.

Similarly, with respect to unilateral withholding and withdrawal, we do not have clear enough direction from the case law. There are no cases out there that solve the problem for us. There is nothing to get the legislators off the hook, so to speak — to be unsympathetic about it — for the absence of responses to the unanimous recommendations made by the Special Senate Committee on Euthanasia and Assisted Suicide, because you could have resolution through the case law, but we have not seen it. It is coming, and if the legislators do not move, I believe that, within five years, we will have something from the Supreme Court on the mature minor issue and on the unilateral withholding and withdrawal issue. They will be forced to deal with those

**Le sénateur Beaudoin:** C'était une décision cinq à quatre. Nous considérons que la cause *Rodriguez* est claire pour ce qui est du suicide assisté, et c'est tout ce que nous disons, rien de plus, rien de moins. Pour les deux autres questions, l'interruption et le refus, il reste beaucoup à faire.

J'aimerais savoir si vous considérez ou non que la jurisprudence a jeté quelque lumière sur cette question, parce que vous avez analysé un certain nombre de cas depuis 1995, et il est évident que toutes les informations que vous pourriez nous donner pourraient nous aider à prendre nos décisions.

**Mme Downie:** Prenons un ou deux exemples de zones grises concernant le refus et l'interruption et considérons les cas pertinents. Un de ces exemples porte sur des mineurs mûrs. Comme vous l'avez vous-même reconnu, la question n'est pas claire. Vous disiez bien que la compétence relève des provinces, si bien que nous avons dans certaines provinces une législation qui précise que le refus de traitement par des mineurs doit être respecté même s'il y a une certaine confusion dans la loi. Parfois il est stipulé que c'est tout refus, si le mineur est capable de prendre une décision, aussi capable qu'un adulte; dans d'autres cas, il est stipulé que cela ne s'applique que s'il est capable de prendre une décision et prend cette décision dans son propre intérêt.

Ce n'est pas plus clair en jurisprudence. Nous avons par exemple deux cas importants en Colombie-Britannique. Dans l'un, le juge dit que si on est mineur, mais que l'on comprend la nature et les conséquences de la décision à prendre, le refus doit être respecté, sauf que la cour a toujours compétence *parens patriae*, c'est-à-dire qu'elle peut intervenir si elle estime que le mineur prend une mauvaise décision. Cela revient à dire que la règle du mineur mûr est limitée. Une autre décision a été rendue récemment par la Cour d'appel. Un juge a déclaré dans ce cas qu'il s'agissait de la règle du mineur mûr sans limite, que l'on ne pouvait parler de son intérêt personnel — que cela ne s'applique pas aux adultes et qu'ainsi cela ne doit pas s'appliquer aux mineurs capables de prendre une décision. Un autre juge de la même cause a par contre dit qu'il fallait conserver cette limite, de sorte qu'un mineur doit être capable non seulement de prendre une décision, mais aussi de prendre une décision qui est dans son intérêt personnel.

Je dirais que dans le contexte de mineurs mûrs la jurisprudence ne règle pas du tout la question. Elle l'embrouille plutôt. Du moins la question a-t-elle été examinée — elle ne l'avait pas été par le passé — mais nous n'avons pas de solution claire.

De même, pour ce qui est du refus unilatéral et de l'interruption unilatérale, nous n'avons pas de directives suffisamment claires de la jurisprudence. Il n'y a aucune décision qui ait réglé le problème. Il n'y a rien qui dégage les législateurs de cette responsabilité, car il n'y a pas eu de réactions aux recommandations unanimes du comité spécial du Sénat sur l'euthanasie et le suicide assisté. La jurisprudence aurait pu régler la question, mais ne l'a pas fait. Cela va venir, et si les législateurs n'agissent pas je pense que d'ici à cinq ans nous aurons quelque chose de la Cour suprême au sujet de la question des mineurs mûrs et de l'interruption unilatérale et du refus unilatéral. Elle sera obligée de trancher parce qu'elle sera saisie de certaines causes et qu'elle



issues because the cases will come before the courts and they will carve off little bits and pieces of the issues. *Rodriguez* deals with a certain area and we now have the statement about competent adults. *Nancy B.* stands for something. All the cases will slowly pick away at all the little grey areas regarding withholding and withdrawal.

Eventually, therefore, 10 or 20 years from now, I might be able to tell you that it is clear, and that I can patch it together for you. From this case, I can tell you this; from that case, I can tell you that. At what cost will that be, though, to all those people who will have to take their cases through the system instead of having the whole range of issues dealt with in hearings that cover all of the concerns, at which the best advocates are able to make their cases? All sorts of advocates could be involved in such a setting, as opposed to the constraints you are familiar with in making law by case law. We can get there but it will take a long time and it will cost quite a price. We don't have the cases to help us that we hoped we would have had after five years.

**Senator Beaudoin:** I could not agree more. We should not leave that to the courts. We must accept our responsibility, and introduce and pass legislation.

**Mr. Sneiderman:** The *Nancy B.* case is a decision by a trial court judge, yet the case has had considerable impact. The people who have had to get that message are the physicians. The message they need to get is that a mentally competent patient has the right to refuse treatment, even if, in the physician's considered judgment, the treatment will restore a quality of life that the physician regards as tolerable.

I am sometimes involved in discussions with physicians and with medical students. They all know about this case. I can recall attending a seminar with medical residents, where a nurse was brought in on a gurney, playing the role of *Nancy B.*, and each of the residents would have to go up to her and engage in a conversation. "*Nancy B.*" would begin the conversation by saying it was time to remove the respirator and to let her die, and there would be a discussion between the patient and the medical resident. One of the medical residents was arguing with "*Nancy B.*" and telling her that she could not abide by her request. She explained that, out of her religious convictions, it was simply impossible for her to grant the patient's request. I then commented. I said to her, "There was a sign on Harry Truman's desk: If you can't take the heat, get out of the kitchen. You are going to be a physician and your religious principles are a matter between you and your God. If you feel you cannot comply with her request, then you are obliged to transfer her to another physician, but you have to understand that that is her legal entitlement." She did not respond to me. She looked rather upset with me. Then a number of her fellow residents injected comments supporting what I had said. They said, "Look, you heard her. She said disconnect the respirator, and she is mentally competent. You can talk to her, you can certainly attempt to persuade her otherwise, you cannot coerce her, but the bottom line

tranchera petit à petit sur ces questions. *Rodriguez* porte sur un point particulier, et nous avons maintenant un énoncé sur les adultes capables de prendre une décision. *Nancy B.* signifie quelque chose. Toutes les causes reprendront petit à petit toutes les petites zones grises concernant le refus et l'interruption.

Ainsi, dans 10 ou 20 ans, je pourrais peut-être vous dire que c'est clair et que l'on a un tableau complet de la question. Je puis vous dire ceci à la suite du jugement rendu dans cette cause; cela à la suite du jugement rendu dans cette autre cause. Qu'en coûtera-t-il, toutefois, à tous ces gens qui devront s'en remettre aux tribunaux plutôt que de devoir régler ces questions dans le contexte d'audiences qui couvrent l'ensemble du sujet? D'autres sortes de groupes pourraient être entendus pour mettre au point les dispositions législatives voulues alors que le recours à la jurisprudence présente de nombreuses limites. C'est possible, mais cela prendra beaucoup de temps et coûtera très cher. Nous n'avons pas pour nous aider les causes que nous aurions espéré avoir après cinq ans.

**Le sénateur Beaudoin:** Je suis tout à fait d'accord. Nous ne devrions pas laisser cela aux tribunaux. Nous devons accepter nos responsabilités et présenter et adopter un projet de loi.

**M. Sneiderman:** La cause de *Nancy B.* est une décision d'un juge de première instance, mais elle a eu une incidence considérable. Ceux qui ont dû comprendre le message sont les médecins. Le message qu'ils doivent comprendre, c'est qu'un patient qui a les compétences mentales pour prendre une décision a le droit de refuser un traitement même si, de l'avis du médecin, ce traitement lui redonnerait une qualité de vie que le médecin juge tolérable.

Je participe parfois à des discussions avec des médecins et des étudiants en médecine. Ils connaissent tous cette cause. Je me rappelle avoir assisté à un séminaire avec des étudiants et résidents en médecine où l'on a fait venir une infirmière sur une civière qui jouait le rôle de *Nancy B.*, et chacun des résidents devait s'approcher d'elle et entamer une conversation. "*Nancy B.*" commençait la conversation en disant qu'il était temps de retirer l'appareil respiratoire et de la laisser mourir, et la discussion commençait entre la patiente et l'étudiant. Une des étudiantes lui a dit qu'elle ne pourrait se plier à sa demande. Elle a expliqué que, du fait de ses convictions religieuses, il lui était simplement impossible de satisfaire à la demande de la patiente. J'ai alors pris la parole. Je lui ai dit: «Il y avait une pancarte sur le bureau de Harry Truman qui disait: Si vous ne supportez pas la chaleur, sortez de la cuisine. Vous allez être médecin, et vos principes religieux sont une question entre vous et votre Dieu. Si vous avez l'impression que vous ne pouvez respecter sa demande, vous êtes tenue de la confier à un autre médecin, mais vous devez comprendre que c'est son droit.» Elle ne m'a pas répondu. Elle avait l'air assez mécontente. Puis un certain nombre de ses confrères ont fait des commentaires appuyant ce que j'avais dit. Ils ont déclaré: «Écoute, tu as entendu. Elle t'a dit de débrancher l'appareil respiratoire, et elle est capable de prendre cette décision. Tu peux lui parler, tu peux certainement essayer de la persuader

is that it is her decision.” This decision by a trial judge has had a considerable impact.

[Translation]

**Senator Pépin:** I was a nurse at a time when we had to refuse to give morphine to a patient, even if he or she was in a great deal of pain, if we knew that, given the patient’s weakstate, the morphine injection could be fatal. Later on, the legislation as well as the Catholic position changed, so that nurses were allowed to give morphine to such patients.

Ms Downie, you said that a minor could be considered to be an adult if he or she has a good understanding of the legislation and if the request is clear. However, a court or a doctor could decide otherwise if the request cannot be granted. Let us take, for example, the case of a 15-year old minor with leukaemia, who would find the treatment too painful and ask that it be discontinued, could a doctor, a judge or a parent object to the request? I am not too sure about that.

A few years ago, the age of majority for medical treatment was different from one province to the next. Is that still the case? Out of all the Canadian provinces, Quebec had the lowest age of majority at the time. The age of majority in Newfoundland was 19, whereas in Quebec, you only had to be 14 or 15 to get the pill, for instance.

[English]

**Ms Downie:** First, the age of the minor does vary from province to province. There is age of majority legislation in every province, and it applies from age 18, 19 and up. Quebec has legislation that governs consent of minors and refusal of treatment down to age 14; and that province has had that legislation longer than any province has had similar legislation. You do find this somewhat odd situation.

**Senator Pépin:** Could a child of 14 be authorized to do something as compared to someone who is considered to be a minor at age 18 in another province?

**Ms Downie:** Yes, exactly. You also have a problem in that you are 17 years and 364 days old, yet you cannot consent. However, two days later you can. What happens to a person’s competence in a 48-hour period? That is the absurdity of linking consent to age.

In the common law, we have moved away from that. There is recognition that it should be about competency and not about age, and that you do a competency test for every minor as you do for every adult. If you find that someone under the age of majority is capable of understanding the nature and the consequences of the decision, then they should be the decision maker. That is the start of the mature minor rule that is reflected in some provinces through legislation, but not in all provinces. There is muddying of the rule because in some places it is an unlimited rule and in others the decision must be “in the best interests” of the person. You can imagine a situation where you have a 15 year old who has end-stage leukemia and is clearly dying. This teenager has a

d’autre chose, mais tu ne peux la forcer, car, en définitive, c’est à elle de décider.» Cette décision d’un juge de première instance a eu une incidence considérable.

[Français]

**Le sénateur Pépin:** J’étais infirmière à l’époque où l’on devait refuser de donner une injection de morphine à un patient très souffrant si on savait, étant donné sa faiblesse, qu’il pouvait en mourir. Plus tard, la loi et la religion catholique ont changé, ce qui a permis aux infirmières de le faire.

Mme Downie vous dites qu’un mineur peut être considéré d’âge adulte lorsqu’il comprend très bien la loi et que sa demande est claire. Par contre, la cour ou un médecin peut décider du contraire si on ne peut pas répondre à sa demande. Prenons l’exemple d’un mineur de 15 ans atteint de leucémie, trop souffrant et qui ne veut pas poursuivre les traitements. Est-ce qu’un médecin, la cour ou un parent pourrait s’opposer à sa demande? Cela n’est pas clair pour moi.

Il y a quelques années l’âge de la majorité, pour les traitements médicaux, variait d’une province à l’autre, est-ce encore le cas? Le Québec était la province où les majeurs étaient les plus jeunes à travers le Canada. À Terre-Neuve, l’âge de la majorité était de 19 ans alors qu’au Québec l’âge requis pour obtenir des moyens de contraception était de 14 ou 15 ans.

[Traduction]

**Mme Downie:** Tout d’abord, l’âge du mineur varie effectivement d’une province à l’autre. Il existe dans chaque province une loi sur l’âge de la majorité, et elle s’applique à partir de l’âge de 18, 19 ans et plus. Au Québec il existe une loi qui régit le consentement des mineurs et le refus de traitement à partir de l’âge de 14 ans; et cette loi est en vigueur dans cette province depuis plus longtemps que dans n’importe quelle autre province ayant des lois similaires. On constate donc ce genre de situation assez étrange.

**Le sénateur Pépin:** Un enfant de 14 ans pourrait-il être autorisé à faire quelque chose comparativement à un jeune qui est considéré comme un mineur à l’âge de 18 ans dans une autre province?

**Mme Downie:** Oui, tout à fait. Il y a également le problème du jeune qui a 17 ans et 364 jours et qui pourtant ne peut pas donner son consentement. Cependant, deux jours plus tard, il le peut. Qu’arrive-t-il à la compétence d’une personne dans une période de 48 heures? C’est toute l’absurdité de lier le consentement à l’âge.

En common law, on ne voit plus les choses de cette façon. On reconnaît qu’il doit s’agir de la compétence et non de l’âge, et qu’on doit administrer un test de compétence à chaque mineur comme on le fait pour chaque adulte. Si vous constatez que quelqu’un qui n’a pas encore atteint l’âge de la majorité est capable de comprendre la nature et les conséquences de la décision, alors ce devrait être à cette personne de prendre la décision. C’est le début de la règle du mineur mûr dont fait état la législation de certaines provinces, mais pas de toutes les provinces. La règle n’est pas claire, car dans certains endroits il s’agit d’une règle illimitée et dans d’autres la décision doit être prise «dans l’intérêt véritable» de la personne. On peut imaginer



poor prognosis and has undergone all kinds of chemotherapy. However, this minor understands the situation and says, "Enough is enough. I refuse to continue." The judges may say — and, we have a trilogy of cases on teenagers refusing life-sustaining treatment — "Absolutely. Yes. Your refusal should be respected." In each of those cases, the judges understand the decision and they recognize it. If they are putting themselves in that minor's shoes they are thinking to themselves, "That is what I would do." It is a reasonable decision in their minds. The question is: What happens when the minor is making a decision that the judges do not think is reasonable? That is where you get this inclination to have a "best interests" tag on the mature minor rule. That is dangerous because you start to get into assessing the quality of someone's judgment. We do not do that for adults, so why are we doing it for 17 year olds? For 364 days of the year they must make only the right decision, but adults can make the most foolish decisions in the world and we will not interfere. It will be interesting to see the case where a judge is not sympathetic to a decision of a 15 year old regarding the refusal of treatment. The judge may think it is a poor decision. If a case like that were to go to the Supreme Court, we would get an answer to the mature minor issue.

**Mr. Sniderman:** Keep in mind that, from an historical perspective, the mature minor rule developed in the context of cases of minors seeking treatment for not only sexually transmitted diseases but also birth control. The stress was not so much upon the decision-making process of the minor but the fact that the treatment being requested clearly served the minor's best interest. The phrase "mature minor" refers to the competency of the minor. We do not have a clear legal definition of mental competency, and we probably never will.

We must also keep in mind that adolescent decision making is not necessarily the same as adult decision making. There was a case in Saskatchewan of a 12-year-old boy who had cancer. His father was refusing to consent to the medically recommended treatment which entailed the amputation of part of his leg. The child expressed his own deep convictions that he agreed with his father. That case attracted partisans on both sides.

We know that adolescents tend to be more influenced by their peers and by their parents than by adults. We also know that adolescents are often more concerned about bodily appearance than are adults. I know of a case in Winnipeg of a 16 year old who refused to consent to chemotherapy because she would lose her hair. She insisted that she would rather die than lose her hair. Her mother said, "We will get you a wig." The girl replied, "It is not the same!" She did, however, receive the chemotherapy, and there was no court proceeding. She was simply told that the treatment would be administered whether or not she liked it.

une situation où un jeune de 15 ans est atteint de leucémie en phase terminale, un jeune dont les jours sont clairement comptés. Le pronostic pour cet adolescent est sombre, bien qu'il ait suivi toutes sortes de traitements de chimiothérapie. Cependant, le mineur en question comprend la situation et dit: «C'est assez, je refuse de continuer.» Les juges peuvent décider — et nous avons une trilogie de cas d'adolescents qui ont refusé le traitement de maintien en vie: «Absolument. Oui. Votre refus doit être respecté.» Dans chacun de ces cas, les juges comprennent la décision et la reconnaissent. S'ils se mettent à la place du mineur, ils se disent: «C'est ce que je ferais.» À leur avis, il s'agit d'une décision raisonnable. La question qui se pose est la suivante: que se passe-t-il lorsque le mineur prend une décision que les juges ne considèrent pas comme raisonnable? C'est là qu'on a tendance à accoler cette notion «d'intérêt véritable» à la règle du mineur mûr. Cela est dangereux parce qu'on se trouve alors à évaluer la qualité du jugement d'une personne. Nous ne le faisons pas dans le cas des adultes, alors pourquoi le faisons-nous dans le cas des adolescents de 17 ans? Pendant 364 jours de l'année, ils doivent prendre uniquement la bonne décision, mais les adultes peuvent prendre les décisions les plus ridicules du monde, et nous n'interviendrons pas. Il serait intéressant de voir ce qui se passerait si un juge n'appuyait pas la décision d'un jeune de 15 ans qui refuse un traitement. Le juge peut considérer que ce n'est pas une bonne décision. Si un cas de ce genre devait être porté devant la Cour suprême, nous obtiendrions une réponse à cette question de mineur mûr.

**M. Sniderman:** Il ne faut pas oublier qu'historiquement la règle du mineur mûr s'est développée dans le cas de mineurs voulant obtenir un traitement non seulement pour des maladies transmises sexuellement, mais aussi pour la planification des naissances. L'accent ne portait pas tant sur le processus de prise de décisions du mineur que sur le fait que le traitement demandé servait clairement l'intérêt véritable du mineur. L'expression «mineur mûr» désigne la compétence du mineur. Nous n'avons pas de définition juridique claire de la compétence mentale, et nous n'en aurons probablement jamais.

Il ne faut pas non plus oublier que les décisions prises par des adolescents ne sont pas nécessairement les mêmes que les décisions prises par des adultes. Il y a eu le cas en Saskatchewan d'un jeune garçon de 12 ans atteint du cancer. Son père refusait de consentir au traitement recommandé par les médecins, qui comportait l'amputation d'une partie de sa jambe. L'enfant a exprimé ses propres convictions, à savoir qu'il était d'accord avec son père. L'affaire a suscité l'intérêt de partisans des deux camps.

Nous savons que les adolescents ont tendance à être influencés davantage par leurs pairs et par leurs parents que par des adultes. Nous savons aussi que les adolescents sont souvent plus préoccupés par leur apparence physique que ne le sont les adultes. Je suis au courant d'un cas à Winnipeg où une jeune fille de 16 ans a refusé de consentir à la chimiothérapie parce que ce traitement lui ferait perdre ses cheveux. Elle a insisté sur le fait qu'elle préférerait mourir que perdre ses cheveux. Sa mère lui a dit: «Nous t'achèterons une perruque.» La jeune fille a répondu: «Ce n'est pas la même chose!» Elle a toutefois subi des traitements de chimiothérapie, et il n'a pas été nécessaire d'aller devant les

There is also the question of short-term versus long-term consequences because adolescents are often more concerned about the short term than the long term.

This is a complex issue. We can say that, if the minor is mentally competent then the minor must decide because, if we only let the minor decide when we as adults agree that the decision serves the best interest of the minor, then we are making a mockery of the rule. The question remains: When is the minor mentally competent to decide? As Ms Downie pointed out, the cases that have been decided have all involved cases with rather grim prognoses, so they are easy to decide. It is playing the numbers game. If the medical witnesses testify that, even with aggressive treatment, the odds of a successful outcome are 10 or 20 per cent, you must assess whether it is worth it. As Ms Downie pointed out, you are the judge. You place yourself in the shoes of the minor and you say, "I would decide as that minor has decided." What we have yet to face is a case where there is an excellent prognosis for recovery and the minor is refusing life-prolonging treatment.

**Senator Pépin:** The other issue concerned medical students. You told us about the medical student who was refusing treatment based on her religious beliefs.

**Mr. Sneiderman:** She was a resident.

**Senator Pépin:** She was a resident. Currently, medical students and nurses are lobbying to be transferred from one department to another one because, for example, they may be working in a department where they must assist in abortions and they can not do so. I understand the lobby is quite strong.

I have not been involved on a hospital floor for many years, but I do remember the impact of the discussion surrounding birth control and the persuasion it took before nurses would cooperate. Of course, the impact of that is not comparable to what we are discussing now.

What trends are young medical students adopting?

**Mr. Sneiderman:** I really cannot say, but I can tell you something about medical students in Manitoba.

**Senator Pépin:** Are they more inclined to accept what the patient says and to help the patient?

**Mr. Sneiderman:** I think that the new generations of medical students and physicians are more respectful of patients' rights than their predecessors. There may be two reasons for that: First, a recognition that the principle of patient autonomy means something, and second, the fear of being sued for disregarding the patient's instructions. That may be even more effective.

tribunaux. On lui a simplement dit que le traitement lui serait administré, qu'elle le veuille ou non.

Il y a aussi la question des conséquences à court terme par rapport aux conséquences à long terme parce que les adolescents sont souvent plus préoccupés par le court terme que par le long terme.

C'est une question complexe. Nous pouvons dire que si le mineur est apte à décider, alors il doit prendre la décision, car si nous laissons le mineur décider lorsque nous, les adultes, convenons que la décision est dans l'intérêt véritable du mineur, nous nous trouvons alors à bafouer la règle. La question demeure: quand le mineur est-il apte à décider? Comme Mme Downie l'a indiqué, les cas où une décision a été rendue étaient tous des cas où les pronostics étaient plutôt sombres: donc il était facile de trancher. C'est le jeu des probabilités. Si les témoins médicaux établissent que même avec un traitement agressif les chances de s'en sortir sont de 10 ou 20 p. 100, vous devez évaluer si cela en vaut la peine. Comme Mme Downie l'a souligné, vous êtes le juge. Vous vous mettez à la place du mineur et vous vous dites: «Je prendrais la même décision que celle prise par le mineur.» Nous n'avons pas encore été saisis d'un cas où le pronostic de rétablissement serait excellent, mais où le mineur refuserait des soins visant à prolonger sa vie.

**Le sénateur Pépin:** L'autre question concerne les étudiants en médecine. Vous nous avez parlé d'une étudiante en médecine qui a refusé d'administrer un traitement à cause de ses croyances religieuses.

**M. Sneiderman:** C'était une résidente.

**Le sénateur Pépin:** C'était une résidente. À l'heure actuelle, les étudiants en médecine et les infirmières exercent des pressions pour être transférés d'un département à un autre parce que, par exemple, ils peuvent se trouver à travailler dans un département où ils doivent aider à pratiquer des avortements, et ils ne peuvent pas le faire. Je crois comprendre que les pressions exercées sont assez fortes.

Il y a longtemps que je n'ai pas travaillé dans un hôpital, mais je me souviens de l'impact des discussions concernant le contrôle des naissances et de la persuasion dont il a fallu faire preuve avant que les infirmières coopèrent. Bien entendu, cet impact n'est pas comparable à ce dont nous discutons aujourd'hui.

Quelles sont les tendances manifestées par les jeunes étudiants en médecine?

**M. Sneiderman:** Je ne suis pas vraiment en mesure de vous le dire, mais je peux vous parler des étudiants en médecine du Manitoba.

**Le sénateur Pépin:** Sont-ils plus disposés à accepter ce que dit le patient et à aider le patient?

**M. Sneiderman:** Je pense que les nouvelles générations d'étudiants en médecine et de médecins sont plus respectueuses des droits de leurs patients que leurs prédécesseurs, et ce, pour deux raisons: tout d'abord parce qu'ils reconnaissent concrètement le principe de l'autonomie du patient, et deuxièmement parce qu'ils craignent d'être poursuivis s'ils ne suivent pas les instructions du patient. Cela est sans doute encore plus efficace.



**Senator Pépin:** I forgot about that.

**Senator Corbin:** Out of curiosity, in the conscience case to which you alluded where the nurse refused to comply with the patient's wishes, did that event take place in a religious environment? Was this a public hospital? Was the patient of the same faith?

**Mr. Sneiderman:** This was in the context of a seminar organized by one of the professors of medicine who has expertise in medical ethics, and it was an exercise in role playing. This was at the Health Sciences Centre in Winnipeg. The religious convictions of the patient were never discussed. The medical resident referred to her religious convictions but did not specify what they were. She did say something about the sanctity of life and that she simply could not abide the decision by a patient to die. She said it might be different if the patient were terminally ill and dying, but this patient was not. That is all she said.

**Senator Corbin:** It was an ethics game, really?

**Mr. Sneiderman:** I have taken part in a few of these scenarios, and it is interesting how people really get caught up in it. It is not play acting to them; it becomes real.

**Senator Corbin:** We have such thing as war games. That is an analogy.

**Mr. Sneiderman:** Yes.

**Senator Corbin:** The more general question relates to the purpose of this whole exercise, I suppose.

Why have governments or parliaments or assemblies not moved on some of the issues raised in the Senate's report, "Of Life and Death", and for how long will one need to wait before there is action on that front?

Professor Downie, I do not recall your exact terms, but you referred to the courts, case by case, building a societal consensus, and to establishing precedents by bits and pieces. That takes us back to how euthanasia became legal in the Netherlands, for example. The courts ruled where Parliament refused to tread.

Leaving the legality aspect on the side for now, would you have any thoughts about governments and parliaments and assemblies not assuming their responsibilities, social or societal, with respect to this? I may be looking for something political or philosophical, but that is what this is about.

**Ms Downie:** It is a fabulous question. Why has nothing happened? I am not the best person to answer that question. It might take a political scientist together with an anthropologist to come up with an answer.

To be candid, I think it is an abdication of responsibility. I have no trouble reaching that conclusion, but I do have trouble understanding why that is so. Perhaps I do not understand enough about the forces of politics. I look at it from the outside, and it appears to me that this is an issue which is associated with a

**Le sénateur Pépin:** J'avais oublié cet aspect.

**Le sénateur Corbin:** Par curiosité, dans le cas de conscience auquel vous avez fait allusion lorsque l'infirmière a refusé de se conformer au souhait du patient, cet événement a-t-il eu lieu dans un environnement religieux? S'agissait-il d'un hôpital public? S'agissait-il d'un patient de la même religion?

**M. Sneiderman:** C'était dans le contexte d'un colloque organisé par l'un des professeurs de médecine versés en éthique médicale, et il s'agissait d'un exercice de jeu de rôles. Cela se déroulait au Health Sciences Centre à Winnipeg. On n'a jamais discuté des convictions religieuses du patient. La résidente médicale a mentionné ses croyances religieuses sans préciser en quoi elles consistaient. Elle a parlé du caractère sacré de la vie et a indiqué qu'elle ne pouvait tout simplement pas accepter la décision d'un patient de mourir. Elle a dit que la situation serait peut-être différente si le patient était en phase terminale et en train de mourir, ce qui n'était pas le cas. C'est tout ce qu'elle a dit.

**Le sénateur Corbin:** Il s'agissait en fait d'un exercice d'éthique?

**M. Sneiderman:** J'ai participé à quelques-uns de ces exercices, et il est intéressant de constater à quel point les gens se prennent au jeu. En fait ce n'est plus un jeu pour eux; cela devient réel.

**Le sénateur Corbin:** Nous avons les jeux de guerre. C'est une analogie.

**M. Sneiderman:** Oui.

**Le sénateur Corbin:** La question plus générale concerne l'objet de tout cet exercice, je suppose.

Pourquoi les gouvernements, les parlements ou les assemblées législatives n'ont-ils pas donné suite à certaines des questions soulevées dans le rapport du Sénat, «De la vie et de la mort», et combien de temps faudra-t-il attendre avant que l'on agisse à cet égard?

Professeur Downie, je ne me souviens pas de vos termes exacts, mais vous avez dit que les tribunaux sont en train, cas par cas, d'établir un consensus sociétal, et d'établir des précédents, petit à petit. Cela nous rappelle la façon dont l'euthanasie est devenue légale aux Pays-Bas, par exemple. Les tribunaux se sont prononcés là où le Parlement a refusé de s'aventurer.

Laissons de côté l'aspect légal pendant un instant. Que pensez-vous des gouvernements, des parlements et des assemblées législatives qui n'assument pas leurs responsabilités, sociales ou sociétales, à cet égard? J'aimerais que vous abordiez l'aspect politique ou philosophique, car c'est ce dont il s'agit.

**Mme Downie:** C'est une question extrêmement intéressante. Pourquoi n'a-t-on rien fait? Je ne suis pas la personne la mieux indiquée pour répondre à cette question. Il faudrait sans doute un politicologue et un anthropologue pour répondre à une telle question.

Je crois franchement qu'il s'agit d'une abdication de responsabilité. Je n'ai aucune difficulté à arriver à cette conclusion, mais j'ai de la difficulté à comprendre ce phénomène. Je ne comprends peut-être pas suffisamment les influences qui s'exercent au niveau de la politique. Je suis une observatrice de l'extérieur, et il me

polarizing issue. I am talking only about the unanimous recommendation. I am not talking about decriminalizing euthanasia. It is about withholding and withdrawal of life-sustaining treatment. Why will people not touch that issue? I think they fear that, if you introduce legislation in this arena, people will think you are already introducing legislation on euthanasia and assisted suicide, and that you are disguising the issue in sheep's clothing. They may fear that you are taking that first step and that we will not be able to stop the slide down the slippery slope. The fear that attaches to a polarizing issue relates to the outcome of the vote on it. There are very vocal minorities in this area who seem to carry a lot of political clout. It is perfectly clear that the vast majority of Canadians support this kind of legislative reform, yet obviously the calculation being conducted by those who figure out what we will and will not touch as elected politicians is: What will or will not get us re-elected? The consensus is that this will not lead to re-election. I think that is very unfortunate.

I believe that people have a responsibility to do this. I hope that you will do it, that you carefully educate the public, and that you reap enormous rewards for doing it. This is an intriguing opportunity for the Senate to do something. You do not need to think about getting re-elected. You can put aside all those political questions and recognize that we have a serious problem here in Canada in that we are not caring properly for the dying. You need not open up the other debate, but you can touch a part of it and do something about it. People will applaud you for doing so if it is done carefully, and we will be better able to care for the dying. Most health workers will be better able to do that, and most of them want to do that. How can we lose? We can get away from the politics and focus on the point of it all, which is enabling everyone to care for the dying through law reform which is not controversial in its content. I would throw the question back to you and ask why it has not happened from the outside.

**Senator Corbin:** I am of the same view. I am also bothered by this lack of action.

I do not want to get into religious perspectives in relation to this matter, but even the Vatican is in agreement on some items in our report. I do not believe the public is broadly aware of that, and I do not believe governments are broadly aware of what is meant by a do not resuscitate order, artificial life support and that sort of thing. The Vatican has clearly expressed its views on that. Professor Sniderman may wish to add to that.

**Mr. Sniderman:** In 1957, Pope Pious XII, who is not one of my heroes, drew a distinction between extraordinary and ordinary treatment. Now one hears the distinction between proportionate and disproportionate treatment. The church at that time stated that, if treatment offers no reasonable hope of benefit, it need not be applied.

semble que c'est une question qui a tendance à polariser l'opinion. Je ne parle pas uniquement de la recommandation unanime. Je ne parle pas de la décriminalisation de l'euthanasie. Je parle de la non-administration et de l'interruption du traitement de survie. Pourquoi les gens refusent-ils d'aborder cette question? Je pense qu'ils craignent que, si vous présentez une loi dans ce domaine, les gens ne croient que vous êtes déjà en train de présenter une loi sur l'euthanasie et le suicide assisté, et que vous êtes en train de déguiser la question. Ils craignent peut-être que vous ne fassiez ce premier pas et que nous n'arrivions pas à nous arrêter une fois lancés sur cette pente glissante. La crainte qui se rattache à une question qui suscite la polarisation concerne le résultat du vote sur une telle question. Il existe dans ce domaine des minorités qui se font entendre et qui semblent avoir beaucoup d'influence sur le plan politique. Il est parfaitement clair que la grande majorité des Canadiens appuient ce type de réforme législative: pourtant il est évident que les calculs faits par ceux qui déterminent ce qui influera sur les politiciens élus consistent à déterminer ce qui permettra de les faire réélire. Le consensus à cet égard, c'est que cela ne favorisera pas la réélection. Je pense que c'est très malheureux.

J'estime que les gens ont une responsabilité à cet égard. J'espère que vous l'assumerez, que vous informerez soigneusement le public et que vous en récolterez d'énormes avantages. Il s'agit d'une occasion intéressante d'agir pour le Sénat. Vous n'avez pas besoin de vous préoccuper de votre réélection. Vous pouvez mettre de côté tous ces aspects politiques et reconnaître qu'il existe un problème grave au Canada, à savoir que nous ne nous occupons pas correctement des mourants. Il n'est pas nécessaire d'ouvrir l'autre débat, mais vous pouvez en aborder un aspect et prendre des mesures à cet égard. Les gens vous applaudiront si cela est fait soigneusement, et nous serons mieux en mesure de nous occuper des mourants. La plupart des travailleurs de la santé seront mieux en mesure de le faire, ce que d'ailleurs ils veulent faire. Nous n'avons rien à perdre. Nous pouvons laisser de côté la politique et mettre l'accent sur la question fondamentale, à savoir permettre à tous de soigner les mourants grâce à une réforme législative dont la teneur n'est pas controversée. Je vous renvoie la balle et vous demande pourquoi cela ne s'est pas produit de l'extérieur.

**Le sénateur Corbin:** Je partage votre opinion. Cette inertie me dérange moi aussi.

Je n'ai pas l'intention d'aborder l'aspect religieux de cette question, mais même le Vatican approuve certains des points soulevés dans notre rapport. Je ne crois pas que le public en général soit au courant de la chose, et je ne crois pas non plus que les gouvernements sachent ce que l'on entend par une ordonnance de non-réanimation, par le maintien en vie artificiel et ce genre de choses. Le Vatican a clairement exprimé ses vues à cet égard. Le professeur Sniderman a peut-être des choses à ajouter.

**M. Sniderman:** En 1957, le pape Pie XII, qui n'est pas l'un de mes héros, a établi une distinction entre un traitement extraordinaire et ordinaire. Aujourd'hui on parle de distinction entre un traitement proportionné et disproportionné. L'Église à cette époque avait déclaré que si le traitement n'offre aucun espoir de bienfait, il était inutile de l'appliquer.



Many Catholic priests still do not get that message. I know of cases in Winnipeg where there were family conflicts and where the priest said that the patient had to be treated because life is sacred. The priest did not understand what his own church dictated more than 40 years ago.

As well, there may be definitional confusion surrounding the term "euthanasia". Whenever I take part in a forum about assisted suicide and euthanasia, I very carefully define the terms. There was a time when a distinction was drawn between passive euthanasia and active euthanasia. Those terms have fallen by the wayside. What was called active voluntary euthanasia is what is now meant by euthanasia in the debate over the legalization of assisted suicide and euthanasia. The termination of life-prolonging treatment is now simply called "the termination of life prolonging treatment". It is no longer called passive euthanasia. The word "euthanasia" raises a red flag. To some people, "termination of life-prolonging treatment" is euthanasia, and if that is euthanasia there must be something wrong with it. One must be very clear about the definitions.

**Ms Downie:** A more sympathetic interpretation of why nothing has been done is that there have been some very high profile euthanasia and assisted suicide cases over the past few years: Robert Latimer, Nancy Morrison and so on. Perhaps people believe that legislation should not be introduced while there is press coverage of these euthanasia cases because the public will not be able to separate them.

**Senator Corbin:** That will go on forever.

**Ms Downie:** That is an issue. Can that be used as an excuse, because the cases may never end? *Morrison* has been dealt with. Will something else happen before *Latimer* is concluded? The fear of people may be the combining of the euthanasia cases with the withholding/withdrawal legislation. The challenge is to be very careful about the language and to publicize the language so that the public knows what you intend. In that way, I think they will embrace it.

**Senator Pépin:** The palliative care people will listen. However I do recognize that when the word "euthanasia" is used, everyone gets scared.

**Mr. Sneiderman:** In my opening remarks I said that I would comment on the *Morrison* case, and I forgot to do so. With your permission, I would like to do so now.

**The Chairman:** Yes, please.

**Mr. Sneiderman:** In his decision at the preliminary hearing, the judge said, first, that there was really no case to go to the jury on the question of murder, and that was because there was some evidence that the massive amounts of pain killing drugs that had been administered to the patient were not getting through because the IV had become dislodged. There was a theory that if those drugs were not getting through, perhaps the potassium chloride was not getting through. However, the fact is that one minute after

Un grand nombre de prêtres catholiques n'ont toujours pas compris ce message. Je suis au courant de cas à Winnipeg où il y avait des conflits familiaux et où le prêtre a déclaré que le patient devait être traité parce que la vie est sacrée. Le prêtre n'avait pas compris ce que sa propre Église avait prescrit il y a plus de 40 ans.

Par ailleurs, la définition du terme «euthanasie» risque de prêter à confusion. Chaque fois que je participe à une tribune sur l'aide au suicide et l'euthanasie, je prends la peine de définir très soigneusement les termes. Il y a une époque où on établissait une distinction entre l'euthanasie passive et l'euthanasie active. Ces termes ont depuis été abandonnés. Ce que l'on appelait l'euthanasie active volontaire, c'est ce que l'on appelle maintenant l'euthanasie dans le débat sur la légalisation de l'aide au suicide et de l'euthanasie. Ce que l'on appelait l'euthanasie passive est désignée désormais par l'expression «cessation des soins visant à prolonger la vie». Lorsqu'on utilise le mot «euthanasie», c'est comme agiter un drapeau rouge. Pour certaines personnes, la cessation des soins visant à prolonger la vie équivaut à l'euthanasie, et si cela équivaut à l'euthanasie, alors ce doit être quelque chose de répréhensible. Il faut être très clair à propos des définitions.

**Mme Downie:** Une interprétation un peu plus indulgente des raisons pour lesquelles rien n'a été fait, c'est qu'au cours des dernières années il y a eu certains cas d'euthanasie et d'aide au suicide qui ont retenu l'attention du public: Robert Latimer, Nancy Morrison, et cetera. Certains estiment peut-être qu'il ne faut pas présenter de loi pendant que ces cas d'euthanasie font les manchettes parce que le public ne sera pas en mesure de faire la distinction.

**Le sénateur Corbin:** Cela ne finira jamais.

**Mme Downie:** C'est un problème. Peut-on utiliser cela comme prétexte, le fait que ces affaires sont toujours en instance? Une décision a été rendue dans l'affaire *Morrison*. Se produira-t-il autre chose avant que la décision soit rendue dans l'affaire *Latimer*? Les gens craignent peut-être que l'on n'allie les cas d'euthanasie avec la loi sur l'abstention ou l'interruption de traitement. L'enjeu consiste à être très prudent dans la façon de présenter les choses, et à présenter les choses de façon à ce que le public sache quelle est votre intention. Je crois qu'ainsi on obtiendra son adhésion.

**Le sénateur Pépin:** Les responsables des soins palliatifs vont écouter. Cependant je reconnais effectivement que le mot «euthanasie» effraie tout le monde.

**M. Sneiderman:** Dans mes déclarations préliminaires, j'ai dit que je commenterai l'affaire *Morrison*, et j'ai oublié de le faire. Avec votre permission, j'aimerais le faire maintenant.

**La présidente:** Oui, je vous en prie.

**M. Sneiderman:** Dans sa décision lors de l'audience préliminaire, le juge a déclaré tout d'abord qu'il n'y avait pas vraiment lieu de demander à un jury de se prononcer sur la question de meurtre, étant donné que selon certaines indications la perfusion des quantités massives de médicaments antidouleur qui avaient été administrées au patient ne s'était pas faite parce que l'intraveineuse avait bougé. On avait avancé la théorie selon laquelle si la perfusion de ces médicaments ne s'était pas faite, il

the potassium chloride was administered, the patient's heart stopped. Therefore, I think that there was a prima facie case to go to the jury.

Aside from that, however, the decision that there was no included offence that could be proven against Dr. Morrison was clearly wrong, because there was uncontested evidence that she administered potassium chloride and that clearly, in law, is the crime of attempted murder. According to the Criminal Code, even if it is factually impossible to commit the offence, an accused can still be convicted of an attempt.

One example I use with students is grandma rocking in her rocking chair. You are the heir of her estate and she just will not die so you pump her full of lead. It turns out, on autopsy, that granny died of a heart attack ten minutes before you shot her. That is still attempted murder. You cannot kill a corpse so you cannot be convicted of murder, but it is attempted murder, as is the *Morrison* case.

It is interesting to question why, in the face of what I think is clearly the law, this case was brought to a close, although that is not to say that I think that was not the best result given the circumstances of the case.

**Senator Roche:** Professor Downie, I read the article in *The Globe and Mail* today entitled "Why we should embrace death". The author is Daryl Pullman, who is Associate Professor of Medical Ethics at Memorial University in St. John's. He makes some rather interesting juxtapositions between the appropriate role of the physician and the inevitability and mystery of death. He then distinguishes between advancing medical science and a death denying culture.

There are terrible complexities in this issue with regard to how to protect the integrity and sanctity of life, on the one hand, while at the same time protecting the rights of health care providers and the rights of patients.

What would you like this committee to do? Is it unfair of me to ask you to sum up your view? When people ask me to sum up my philosophy, I tell them to read my books. Are you able to tell this committee, from your experience, what you would like this committee to recommend with respect to the juxtaposition that I put to you about retaining the sanctity of life and protecting the rights of physicians, health care providers, and patients?

**Ms Downie:** I will give you a limited answer to that question. I will limit it to the context of the unanimous recommendations; therefore, what to do about the issues that were tackled in those unanimous recommendations.

If you look at the core values in our legal system, which I think are quite widespread throughout society, you find the values you have expressed in the language of rights. You find autonomy, equality, dignity, life. Those are clearly the core values of our

en était peut-être de même pour le chlorure de potassium. Cependant, le fait est qu'une minute après que le chlorure de potassium eut été administré, le coeur du patient a cessé de battre. Par conséquent, je crois qu'il s'agissait d'une cause probable d'action à soumettre au jury.

Par ailleurs, la décision selon laquelle l'existence d'une infraction incluse ne pouvait être établie contre la docteure Morrison était clairement erronée, puisqu'il existait des preuves incontestables selon lesquelles elle avait administré du chlorure de potassium et qu'en droit cela était clairement un crime de tentative de meurtre. Selon le Code criminel, même s'il est dans les faits impossible de commettre le crime, un accusé peut néanmoins être reconnu coupable d'une tentative.

Un exemple que j'utilise avec mes étudiants, c'est celui de la grand-mère qui se berce dans sa chaise berçante. Vous êtes son héritier et, comme elle ne se décide pas à mourir, vous lui trouez la peau. Après l'autopsie, il s'avère que la grand-mère est morte d'une crise cardiaque dix minutes avant que vous lui tiriez dessus. Cela demeure une tentative de meurtre. Comme il est impossible de tuer un cadavre, vous ne pouvez pas être reconnu coupable de meurtre, mais il s'agit d'une tentative de meurtre, comme c'est le cas dans l'affaire *Morrison*.

Il est intéressant de se demander pourquoi, malgré ce qu'indique clairement la loi à mon avis, ce dossier a été clos, même si cela ne veut pas dire que je crois qu'il ne s'agissait pas du meilleur résultat, compte tenu des circonstances de l'affaire.

**Le sénateur Roche:** Professeur Downie, j'ai lu l'article paru dans le *Globe and Mail* aujourd'hui intitulé «Why we should embrace death». L'auteur est Daryl Pullman, professeur agrégé d'éthique médicale à l'Université Memorial à St. John's. Il fait certaines juxtapositions assez intéressantes entre le rôle approprié du médecin et le caractère inévitable et le mystère de la mort. Il fait ensuite la distinction entre l'avancement des sciences médicales et une culture qui nie la mort.

Il s'agit d'une question incroyablement complexe, puisqu'il s'agit d'une part de déterminer comment protéger l'intégrité et le caractère sacré de la vie tout en protégeant les droits des fournisseurs de soins de santé et les droits des patients.

Qu'aimeriez-vous que le comité fasse? Est-ce que j'abuse en vous demandant de résumer votre point de vue à cet égard? Lorsque les gens me demandent de résumer ma philosophie, je leur dis de lire mes livres. Êtes-vous en mesure de dire au comité, d'après votre expérience, ce que vous aimeriez qu'il recommande en ce qui concerne la juxtaposition que je viens de vous présenter à propos de la protection du caractère sacré de la vie et de la protection des droits des médecins, des fournisseurs des soins de santé et des patients?

**Mme Downie:** Je vous donnerai une réponse limitée à cette question. Je la limiterai dans le contexte des recommandations unanimes; par conséquent, ce qu'il faut faire à propos des questions abordées dans ces recommandations unanimes.

Si vous examinez les valeurs fondamentales de notre système judiciaire, qui à mon avis sont assez répandues dans l'ensemble de la société, vous constaterez les valeurs que vous avez exprimées lorsque l'on parle de droits: c'est-à-dire l'autonomie, l'égalité, la



system. They are in tension at times, and in the arena of assisted death they are frequently in tension. However, I think that we find ways of resolving those tensions in other areas that can help us understand how we should resolve them in the area of assisted death.

For instance, with competent adults, throughout our system we have recognized that autonomy prevails as long as no one else is being harmed by the expression of the autonomy. In extremely colloquial terms, it is my right to swing my fist within an inch of the tip of your nose. That runs throughout our legal system and our social fabric. If you apply that to the context of withholding, withdrawal, life-shortening palliative treatment and so on, that tells you that competent adults should have access to potentially life-shortening palliative treatment upon request, and that their refusals of potentially life-sustaining treatment should be respected.

I suggest that the committee ensure that those statements are reflected in the law and in practice such that competent adults have their wishes respected.

You then move to incompetent individuals. If they have advance directives, the autonomy analysis plays out there almost as cleanly. You have a statement of their prior wishes, you know what they would have wanted, so you should respect that and provide the treatment or respect the refusal, as the case may be. With incompetent individuals, we switch to a different form of analysis, the best-interests analysis. It still balances life against other interests. However, it is quite widely accepted that there are times at which life is no longer worth living and you can reasonably say that it is not in the best interests of an incompetent individual to continue to be treated. You can certainly reasonably say that it is in the best interests of an incompetent individual in pain to receive adequate pain control, even if that may shorten his or her life somewhat.

The first priority that I would suggest is to embrace the recommendations yet again, try to find some new way to get them taken up by those who have the power to take them up, and clarify the legal status of withholding and withdrawal of life-sustaining treatment for all categories of individuals. The legal status of the provision of potentially life-shortening palliative treatment must be clarified so that people may receive adequate pain control.

Then you should move to the arena of modifying the sentencing. I do believe that the mandatory minimum life sentence with no possibility of parole for 25 years is inappropriate. It does not serve the interests of society or protect the people we are seeking to protect.

dignité, la vie. Ce sont de toute évidence les valeurs fondamentales de notre système. Il y a parfois des tiraillements entre ces valeurs, et dans le domaine de l'aide à la mort ces tiraillements sont fréquents. Cependant, je pense que nous pouvons trouver des moyens de régler ces tiraillements dans d'autres domaines qui nous permettent de comprendre comment nous devrions les régler dans le domaine de l'aide à la mort.

Par exemple, dans le cas des adultes aptes à décider, dans l'ensemble de notre système nous avons reconnu que l'autonomie prévaut tant que l'expression de cette autonomie ne nuit à personne d'autre. Pour utiliser un langage extrêmement familier, j'ai le droit de brandir mon poing à un pouce de votre nez. Ce principe est répandu dans l'ensemble de notre système judiciaire et de notre tissu social. Si vous l'appliquez dans le contexte de l'abstention, de l'interruption de traitement ou d'un traitement palliatif qui abrège la vie, et cetera, cela signifie que des adultes aptes à décider devraient avoir accès, sur demande, à un traitement palliatif qui risque d'abrèger leur vie, et que leur refus d'un traitement de survie doit être respecté.

Je suggère au comité de s'assurer que le droit et la pratique reflètent ces déclarations de façon à ce que les adultes aptes à décider voient leurs vœux respectés.

Puis on passe aux personnes inaptes à décider. Si elles ont préparé des directives préalables, l'analyse de l'autonomie se fait de façon pratiquement aussi nette. Vous avez une déclaration de leurs souhaits préalables, vous savez ce que ces personnes auraient voulu, donc vous respectez leurs vœux et vous assurez le traitement ou vous respectez le refus du traitement, selon le cas. Dans le cas des personnes inaptes à décider, nous passons à une forme d'analyse différente, l'analyse de l'intérêt véritable. Cette analyse évalue toujours le droit à la vie en fonction d'autres intérêts. Cependant, il est généralement accepté qu'il arrive que la vie ne vaut plus la peine d'être vécue et que l'on peut dire de façon raisonnable qu'il n'est pas dans l'intérêt véritable d'une personne inapte à décider de continuer à recevoir un traitement. On peut dire de façon tout à fait raisonnable qu'il est dans l'intérêt véritable d'une personne inapte à décider, et qui souffre, de recevoir un traitement permettant de contrôler adéquatement la douleur, même si ce traitement risque d'abrèger sa vie.

Je proposerais qu'en premier lieu vous épousiez ces recommandations une fois de plus, que vous tâchiez de trouver une nouvelle façon de les faire adopter par ceux qui ont le pouvoir de les adopter, et de préciser le statut juridique de l'abstention ou de l'interruption de traitement de survie pour toutes les catégories de personnes. Il importe de préciser le statut juridique de la prestation de traitements palliatifs susceptibles d'abrèger la vie afin que les gens puissent recevoir des soins qui soulagent adéquatement la douleur.

Puis vous devriez vous occuper de modifier la peine. J'estime que la peine obligatoire d'emprisonnement à perpétuité sans possibilité de libération conditionnelle pendant 25 ans ne convient pas. Elle ne sert pas les intérêts de la société ni ne protège ceux que nous voulons protéger.

**Senator Roche:** At the back of your brief you talk about dealing with the urgency of why legal clarification is needed. You state:

For example, people are dying in excruciating pain.

Can you point the committee to some empirical evidence as to what kind of numbers would be involved that led you to make that statement?

**Ms Downie:** No. I assume your committee will call not only palliative care experts but individuals who care for people in other kinds of circumstances where there is intractable pain. Not everyone who is dying or everyone who is in intractable pain comes anywhere near a palliative care physician. You will get the most up-to-date data from them. I cannot give you the most up-to-date source. I can provide you with authority for that statement. Certainly, you can also rely on anecdotal evidence.

**Senator Roche:** I would rather not rely on anecdotal evidence. If there is material of a professional nature, I would be happy if you would make that available to the committee.

**Ms Downie:** There is an enormous study coming out in the states, which I believe is called the "Support Study". I can send it to you.

**Senator Roche:** I would have thought that in medical science today people who are in excruciating pain are given sufficient medication.

**Ms Downie:** There are two problems. The first is access to people who know how to manage their pain, whether they be palliative care specialists or other kinds of physicians who know how to manage pain. There is a terrible problem in terms of access to people who know how to control pain. The second problem is that not all pain can be controlled. Even the most fervent palliative care advocates, someone like Dr. Balfour Mount who is a fabulous palliative care provider, will say that at least 5 per cent of people have pain which cannot be controlled.

**Senator Roche:** You also state in your brief:

People are attempting suicide, failing, and ending up in worse shape than before they attempted suicide.

Is there any empirical evidence to support that statement?

**Ms Downie:** There is.

**Senator Roche:** Can you make that available?

**Ms Downie:** Yes.

**Senator Roche:** Professor Sneiderman, given your critical comments on the 10-year sentence for Robert Latimer, can you give the committee your view of what you think an appropriate sentence in such a case should be?

**Le sénateur Roche:** À la fin de votre mémoire, vous dites qu'il est urgent de s'occuper des raisons pour lesquelles un éclaircissement juridique s'impose. Vous déclarez:

Par exemple, les gens meurent dans des souffrances atroces.

Pouvez-vous fournir au comité certaines preuves empiriques quant aux chiffres qui existent et qui vous incitent à faire une telle déclaration?

**Mme Downie:** Non. Je suppose que votre comité convoquera non seulement des spécialistes en soins palliatifs, mais aussi des personnes qui s'occupent de gens dans d'autres circonstances où la douleur est irréductible. Ce ne sont pas tous les mourants ni tous ceux qui éprouvent une douleur irréductible qui reçoivent les soins palliatifs d'un médecin. Ce sont eux qui pourront vous fournir les données les plus à jour. Je ne suis pas en mesure de vous fournir la source la plus à jour. Je peux vous indiquer la source de cette déclaration. Vous pouvez aussi vous fier sûrement à des preuves empiriques.

**Le sénateur Roche:** Je préférerais ne pas me fier à des preuves empiriques. S'il existe des documents professionnels, je serais heureux que vous les mettiez à la disposition du comité.

**Mme Downie:** Il y a une énorme étude faite aux États-Unis intitulée, je crois, «Support Study». Je peux vous l'envoyer.

**Le sénateur Roche:** J'aurais cru que, vu l'état de la médecine aujourd'hui, les gens qui éprouvent des souffrances intolérables se voient administrer suffisamment de médicaments.

**Mme Downie:** Il y a deux problèmes. Le premier, c'est l'accès à des gens qui savent comment soulager leur douleur, qu'il s'agisse de spécialistes en soins palliatifs ou d'autres types de médecins qui savent comment soulager la douleur. Il existe un terrible problème d'accès aux gens qui savent comment soulager la douleur. Le deuxième problème, c'est que certaines douleurs ne peuvent pas être contrôlées. Même les plus fervents partisans des soins palliatifs, quelqu'un comme le docteur Balfour Mount, qui est un merveilleux fournisseur de soins palliatifs, vous diront qu'au moins 5 p. 100 des gens éprouvent une douleur qui ne peut être contrôlée.

**Le sénateur Roche:** Vous déclarez aussi dans votre mémoire:

Les gens essaient de se suicider, sans succès, et se retrouvent dans une situation pire que lorsqu'ils ont fait leur tentative de suicide.

Existe-t-il des preuves empiriques pour appuyer cette déclaration?

**Mme Downie:** Oui.

**Le sénateur Roche:** Pouvez-vous les mettre à notre disposition?

**Mme Downie:** Oui.

**Le sénateur Roche:** Professeur Sneiderman, compte tenu des critiques que vous avez exprimées concernant la peine de dix ans imposée à Robert Latimer, pouvez-vous indiquer au comité ce que vous considérez comme une peine appropriée dans un cas comme celui-là?



**Mr. Sneiderman:** I find it difficult to do that because I am not a sentencing judge. A judge has to look at a pattern of sentencing to determine the appropriate sentence in a given case.

Given the facts of that case, I thought that Justice Noble's sentence was appropriate. I have manila envelopes filled with newspaper clippings and reported cases of horrific offenders who have committed horrific offences and where not only are the maximum sentences less than what Robert Latimer received, but the actual sentences imposed are considerably less.

The sentencing provisions in the Criminal Code for murder are based on the proposition that murder is the worst crime that can be committed. I think that is often the case. However, I do not believe it is always the case. Keep in mind that the focus of attention has to be not only on the crime but also the criminal. I believe the punishment has to fit not only the crime but also the criminal.

**Senator Roche:** You made that point in your testimony. You threw me off a bit in the opening sentence of your response to my question, if I heard you right the second time, when you said that you thought the sentence for Latimer was appropriate.

**Mr. Sneiderman:** If I said that, then I misspoke.

**Senator Roche:** I will give you this chance to correct yourself. I took it from your opening testimony that you thought the sentence for Mr. Latimer was grossly inappropriate, given the circumstances of the case.

**Mr. Sneiderman:** I thought it was inappropriate, that it was too severe. The 10-year sentence was too severe.

**Senator Roche:** Do you think there should have been any sentencing for Mr. Latimer? If so, what should that sentence be, in your view?

**Mr. Sneiderman:** The defence of necessity was presented in that case. The trial judge at the first trial refused to allow the jury to consider that defence. I believe that was the right decision. It may be that a case will arise in which a defence of necessity may be allowed when the accused has committed a mercy killing. That would probably be easier in a case in which there was the consent of the deceased. When there is not the consent of the deceased, when it is a case of nonvoluntary euthanasia, then it really does establish a dangerous precedent that someone should be allowed to decide that someone else is better off dead. I do not like no-never rules. Hypothetically, one might be able to conjure up a scenario in which that would be an appropriate defence. In the *Latimer* case, I would say that what he did was wrong. The crime has been proven, but then there is the question of the punishment.

As I have indicated, I am not a sentencing judge. I really cannot speak from any experience as to what would be an appropriate sentence in this case. All I can say is that I thought that Justice Noble's sentence was appropriate. That is a sentence with which I certainly can live. I think he should serve some time and,

**M. Sneiderman:** Je trouve cela difficile à faire parce que je ne suis pas un juge qui impose des peines. Un juge doit examiner les tendances de la détermination de la peine pour déterminer la peine appropriée à imposer dans un cas donné.

Compte tenu des faits de cette affaire, je considère que la peine prononcée par le juge Noble était appropriée. J'ai des enveloppes pleines de coupures de presse et d'histoires concernant d'horribles contrevenants qui ont commis d'horribles crimes et dont les peines maximales sont non seulement inférieures à celle reçue par Robert Latimer, mais pour qui les peines réellement imposées sont aussi considérablement moins sévères.

Les dispositions relatives à la détermination de la peine dans le Code criminel en ce qui concerne le meurtre s'appuient sur le principe selon lequel le meurtre est le pire crime qui peut être commis. Je pense que c'est souvent le cas. Cependant, je ne crois pas que ce soit toujours le cas. Il ne faut pas oublier qu'il faut tenir compte non seulement du crime, mais aussi du criminel. Je crois que la peine doit être adaptée non seulement au crime, mais aussi au criminel.

**Le sénateur Roche:** Vous l'avez bien dit dans votre témoignage. Vous m'avez un peu étonné dans votre première phrase en réponse à ma question, si je vous ai bien entendu la deuxième fois, lorsque vous avez dit qu'à votre avis la peine imposée à Latimer était appropriée.

**M. Sneiderman:** Si c'est ce que j'ai dit, je me suis trompé.

**Le sénateur Roche:** Je vais vous donner la possibilité de rectifier vos propos. J'ai déduit de votre déclaration qu'à votre avis la peine imposée à M. Latimer était grossièrement inappropriée, vu les circonstances de l'affaire.

**M. Sneiderman:** Je l'ai trouvée inappropriée, trop lourde. La peine de 10 ans était trop lourde.

**Le sénateur Roche:** Estimez-vous que M. Latimer devait recevoir une peine, quelle qu'elle soit? Dans l'affirmative, quelle aurait-elle dû être à votre avis?

**M. Sneiderman:** Dans cette affaire, on a invoqué la défense de nécessité. Le juge de première instance a interdit au jury d'examiner ce moyen de défense. Je pense qu'il a eu raison. Peut-être un jour la défense de nécessité sera-t-elle autorisée lorsque l'accusé aura commis un meurtre par compassion. Cela serait sans doute plus facile dans un cas où la personne décédée avait donné son consentement. Sans le consentement de la personne décédée, lorsqu'il s'agit d'une euthanasie non volontaire, cela crée un précédent dangereux en vertu duquel quelqu'un pourrait décider qu'il vaut mieux qu'une autre personne soit morte. Je n'aime pas les règles inflexibles. En théorie, on pourrait imaginer une situation où ce pourrait être un moyen de défense acceptable. Dans l'affaire *Latimer*, je dirais que sa conduite a été répréhensible. Il a été prouvé qu'il y a eu crime; se pose ensuite la question du châtement.

Comme je l'ai dit, je ne suis pas un juge qui impose des peines. Je n'ai pas l'expérience qui me permettrait de dire ce qui est approprié en l'espèce. Je dirai seulement qu'à mon avis la peine imposée par le juge Noble était appropriée. Je peux l'accepter sans problème. Je pense qu'il devrait purger une peine d'incarcération,

according to Justice Noble, he would and he did. He received a sentence of one year in custody. He did not serve a year. He was released early, but that generally is what happens in our penal system in relatively short sentences.

**The Chairman:** Professor Downie, you talked about advance directives and you said that there is one province and one territory without legislation. I am assuming the province we are talking about is Prince Edward Island.

**Ms Downie:** No, it is New Brunswick. P.E.I. has passed it but not yet proclaimed it. B.C. has also passed it but not yet proclaimed it, although it is expected to come into force on February 28, 2000. We just received that date last week.

**The Chairman:** Do you know of any attempt on the part of the federal government or, indeed, the provinces collectively, to have one province's advance directive legislation accepted in another province? For example, I live in two provinces, Manitoba and Ontario. I have, because I am concerned, advance directives in both provinces, but if I just had one in Manitoba, would it be respected if I were to have an accident or a terminal illness here in Ontario?

**Ms Downie:** There has not been a collective attempt, to my knowledge, certainly nothing at the federal coordinated level, and nothing has resulted where all the provinces have gotten together to have a reciprocal arrangement. I have, in the back of my mind, a nagging feeling that one of the provinces has something about respecting advance directives from other provinces as long as they follow the basic form of the Ontario 1996 legislation. If we do a careful review, we might find, in discrete pieces of legislation, instances where, if you are close enough, you will be captured.

You will run into problems where some provinces do not have both kinds of advance directives. There are instruction directives and proxy directives. The instruction directive is where I set out the kinds of decisions, and the proxy directive says who should make them. In Nova Scotia, we only have a proxy directive, so if you filled out an Ontario instruction directive, which lays everything out wonderfully clearly, but do not appoint a proxy, you will not be covered by the legislation in Nova Scotia.

I think you could put forward a different kind of argument to have your advance directive respected in another province, other than finding some kind of reciprocal provision in the legislation, and that would be through the common law. We have the case law of *Malette v. Shulman* from the Ontario Court of Appeal which says an advance directive must be respected. If you were in another province, say Nova Scotia, and you had an instruction but not a proxy directive, you would have nothing under the Medical Consent Act, which is what our legislation is called, but I might argue that your instruction directive is a clear statement of your prior wishes and we should be bound by that under the common law as opposed to under the Ontario legislation. Clearly, we would not be bound by the Ontario legislation. What I tell people in gatherings, if they are worried about exactly this, is that they might be able to make that move. It is certainly what I would be

et c'est ce qui s'est passé en application de la décision du juge Noble. Il a reçu une peine d'un an d'incarcération. Il ne l'a pas purgée au complet. Il a bénéficié d'une libération anticipée, mais c'est généralement ce qui se passe dans notre système lorsqu'il s'agit de peines relativement légères.

**La présidente:** Professeur Downie, vous avez parlé de directives préalables et vous avez dit qu'il y a une province et un territoire qui n'ont pas de loi. Dois-je comprendre qu'il s'agit de l'Île-du-Prince-Édouard?

**Mme Downie:** Non, c'est le Nouveau-Brunswick. L'Île-du-Prince-Édouard l'a adoptée, mais ne l'a pas encore proclamée. Même chose pour la Colombie-Britannique, mais la loi est censée entrer en vigueur le 28 février 2000. Nous l'avons appris la semaine dernière.

**La présidente:** Savez-vous s'il y a des efforts de la part du gouvernement fédéral ou de l'ensemble des provinces pour que la loi d'une province sur les directives préalables soit acceptée ailleurs? Par exemple, moi, je réside dans deux provinces, le Manitoba et l'Ontario. Parce que c'est une question qui me préoccupe, j'ai préparé des directives préalables dans les deux provinces, mais si je n'en avais qu'au Manitoba, seraient-elles respectées si j'avais un accident ou une maladie fatale ici en Ontario?

**Mme Downie:** À ma connaissance, il n'y a eu aucun effort collectif, et à coup sûr rien au niveau fédéral, et il n'y a pas d'arrangement réciproque entre les provinces. J'ai vaguement le sentiment qu'une province a quelque chose concernant les directives préalables des autres provinces pourvu que leur forme générale s'inspire de la loi ontarienne de 1996. Si l'on procède à un examen attentif, on constatera peut-être, dans les diverses lois, des cas où, si cela se rapproche assez, les directives seraient appliquées.

Vous allez avoir des problèmes quand les provinces n'ont pas le même genre de directives préalables. Il y a les instructions et il y a les procurations. Dans les instructions, on énonce le genre de décisions à prendre, tandis que dans la procuration on indique qui doit prendre ces décisions. En Nouvelle-Écosse, il n'y a que des procurations, de sorte que si vous remplissez les instructions ontariennes, qui précisent tout admirablement, mais que vous ne désignez pas un fondé de pouvoir, vous ne serez pas couvert par la loi de la Nouvelle-Écosse.

Je pense que l'on pourrait avancer un autre argument pour que vos directives préalables soient respectées dans une autre province — sans chercher une disposition de réciprocité dans la loi — et ce serait en invoquant le common law. Dans la jurisprudence, il y a l'affaire *Malette c. Shulman* de la Cour d'appel de l'Ontario dans laquelle il a été décidé que les directives préalables doivent être respectées. Si vous étiez dans une autre province, mettons la Nouvelle-Écosse, et que vous avez des instructions, mais pas de procuration, vous ne bénéficieriez de rien en vertu de la Medical Consent Act, comme elle s'appelle, mais je pourrais soutenir que vos instructions sont l'expression claire de vos souhaits et que nous devrions nous y tenir en vertu du common law, et non en vertu de la loi ontarienne. Il est évident que nous ne serions pas liés par la loi ontarienne. Quand je rencontre des gens qui se préoccupent de cette question précise, je leur dis qu'ils pourraient



arguing if I had a family member in Nova Scotia and that was happening. I would be arguing the common law application.

It is another way to go, but it is also just an Ontario decision, so we do not have the Supreme Court of Canada speaking on that — although, there is again a little twist. *Malette v. Shulman* is embraced in a paragraph in *Rodriguez*. It recognises that it can rely on the common law in certain situations. It is another example of how, by patchwork, I can make an argument for you, and, by patchwork, we can cover all the different areas of withholding and withdrawal, but it is muddy and complicated. Having legislation in place would make it all so much easier. People who do not have access to someone who spends far too much time thinking about end-of-life issues would be able to have their wishes respected more quickly, certainly, and probably more evenly.

**The Chairman:** Now that we have advance directive legislation in so many provinces, what is your sense of public knowledge about those advance directives? My own personal experience is that, when I talk to Manitobans about the fact that we have had advance directive legislation for a considerable length of time — in fact we predate many of the other provinces — they do not even know there is such legislation in the province. Is there any educational programming going on, to your knowledge, to let people know about their right to draw advance directives?

**Ms Downie:** I do not know of anything that is being done by governments, federal or provincial.

What I have seen are more local initiatives by organizations such as Canadian Pensioners Concerned. They put together a fabulous educational package on advance directives. Throughout the country, pockets of people have recognized that certain groups of seniors have a need to understand what the law is with respect to advance directives in their particular province, that is, how it is done, and they have put together a package. You see those kinds of initiatives, but they are limited in their effect because, although they may reach their audience, they do not reach a wider audience than those people who belong to the group. I do not think it is coordinated well enough.

My experience is similar to yours. People do not know about the legislation in their province. There is the additional element of not having coordinated educational programs, and that arises from our resistance to confronting our mortality. I took advance directives home to my family, and said, "Okay, everyone, sit down and fill these out." I was not greeted with, "Oh, thank you so much." People are reluctant. However, if you provide opportunities, very carefully crafted opportunities, for people to have the conversations they need to have in order to construct good advance directives — and it is always very easy to do a useless advance directive — then we would start to see it happen more. The understanding of them is not widespread, and the completion of them is not widespread.

It is a good initiative. Some of the initiatives that were recommended in here, I did not touch on because I focused on the legal recommendations. However, many of the non-legal recommendations are critically important, focusing around education campaigns, national guidelines and national programs.

invoquer cela. C'est en tout cas ce que je soutiendrais si j'avais un membre de ma famille en Nouvelle-Écosse et que cela se présentait. Je réclamerais l'application du common law.

C'est une autre façon de procéder. De plus, ce n'est qu'une décision ontarienne, et la Cour suprême du Canada ne s'est pas prononcée sur la question, quoique ici encore il y ait une complication. La décision *Malette c. Shulman* est citée dans un paragraphe de la décision *Rodriguez*. On y reconnaît que l'on peut invoquer le common law dans certains cas. C'est une autre façon de montrer comment, en faisant du rapiéage, on peut présenter un argument et, de cette façon, couvrir tous les éléments de l'abstention et de l'interruption, mais c'est vaseux et compliqué. Ce serait beaucoup plus facile s'il y avait une loi. Ceux qui ne connaissent pas quelqu'un qui passe son temps à réfléchir aux derniers moments de la vie pourraient faire respecter leurs souhaits plus rapidement et sans doute de façon plus uniforme.

**La présidente:** Il y a aujourd'hui des lois sur les directives préalables dans de nombreuses provinces. À votre avis, la population est-elle au courant? Quand je dis aux Manitobains que nous avons une loi de ce genre depuis longtemps, bien avant celle d'autres provinces, ils ne le savent pas. Y a-t-il une campagne d'information pour que les gens sachent qu'ils peuvent préparer des directives préalables?

**Mme Downie:** Rien à ma connaissance qui soit fait par les gouvernements, fédéral ou provinciaux.

J'ai plutôt constaté des initiatives locales par des organisations comme la Corporation canadienne des retraités intéressés. Elle a préparé une trousse d'information magnifique sur le sujet. Un peu partout au pays, des groupes ont constaté que certaines personnes âgées avaient besoin de comprendre la loi concernant les directives préalables dans leur province, c'est-à-dire la marche à suivre, et ils ont préparé une trousse d'information. Il y a des initiatives de ce genre, mais leur effet est limité parce que même si elles touchent un auditoire, celui-ci se limite aux membres du groupe. À mon avis, ce n'est pas assez bien coordonné.

J'ai constaté la même chose que vous. Les gens ne connaissent pas la loi de leur province. En plus, il n'y a pas de programme d'information coordonnés, et cela vient du fait que l'on ne veut pas être confronté à sa propre mortalité. J'ai apporté des formulaires de directives préalables chez moi et j'ai dit aux membres de ma famille de les remplir. Ils n'ont pas sauté de joie. Les gens hésitent. Mais si on prenait soin de préparer le terrain et de discuter avec eux de ce qu'il faut pour préparer de bonnes directives — il est toujours très facile d'en préparer de mauvaises — la pratique se généraliserait. Il y a peu de gens qui les comprennent et il y en a peu qui les remplissent.

C'est une bonne initiative. Je n'ai pas commenté certaines de celles qui se trouvent ici parce que j'ai choisi de m'attarder sur les recommandations de nature juridique. Toutefois, beaucoup de recommandations qui ne sont pas d'ordre juridique revêtent une importance cruciale, comme les campagnes d'information, les

They will make an enormous difference, and I hope they are picked up.

**Mr. Sneiderman:** What we need is a major public figure to wind up in an intensive care unit and for the spouse to appear in the media and say, "My spouse has signed an advance directive, is refusing the continuation of life-prolonging treatment and, accordingly, that treatment will be stopped." That happened in 1994 with respect to Richard Nixon and with respect to Jacqueline Kennedy.

Those two cases really prompted increasing knowledge in the United States of health care directives. We realize how important the media is. All it takes is for that kind of a case to be picked up by the media. That can do a lot more than local initiatives.

**The Chairman:** Professor Downie, you were speaking about the confusion in the law as a result of not having clear laws, and one of the issues you used as an example was someone calling you and asking your advice, and you having the luxury of saying, "I can give them advice, because I will not be sued."

In your role with the law school, do you get many calls of that nature?

**Ms Downie:** I do get calls where people describe their situation and ask me if they can stop treatment.

I had one that was particularly poignant because it came in the shadow of the *Morrison* case. If you remember, there was a publication ban in that case, so a lot of people did not know what she had done, and thought it was either withholding of treatment or ever-escalating levels of morphine. There was a huge chill.

I received a call in which I was told of a woman who was being managed at home. The woman was on a respirator and she wanted that to stop. The family wanted it to stop. They all felt it was time to stop. I told them that the law allowed them to do that. They then said, "Nobody will do it," and they asked: "Why will nobody stop the respirator in her home?" The reason is that they are concerned that the doctor would drive up, and since it is a rural community, people would see the doctor's car in the driveway. The doctor's car would leave, and then how much later would the ambulance or the hearse arrive? The fear was that they would be charged with something. I do get these calls.

That was an extreme fear because of the *Morrison* case, which was withholding and withdrawal. They said they would be happy to have her come into hospital and they would do it, because they did not fear that exposure. It would not happen.

Health care providers largely understand that not only may they, but they must, remove life-sustaining treatment that a patient or their surrogate is refusing. However, there is still a chill in people's hearts because of the lack of clarity.

I do not get lots of calls, but I get enough to bother me.

lignes directrices nationales et les programmes nationaux. Cela aiderait beaucoup, et j'espère qu'elles seront appliquées.

**M. Sneiderman:** Ce qu'il faudrait, c'est qu'une personnalité se retrouve aux soins intensifs et que son conjoint se retrouve devant les journalistes et dise: «Mon conjoint a signé des directives préalables, refuse l'acharnement thérapeutique, et pour cette raison les soins seront interrompus.» C'est ce qui est arrivé en 1994 dans le cas de Richard Nixon et dans celui de Jacqueline Kennedy.

Aux États-Unis, ces deux cas ont beaucoup fait pour faire connaître les directives en matière de soins de santé. Nous savons quelle est l'importance des médias. Il suffit qu'un cas comme celui-là retienne l'attention des médias. Cela peut accomplir bien davantage que les initiatives locales.

**La présidente:** Madame Downie, vous dites que les lois ne sont pas claires et donc que la confusion règne. Vous avez donné l'exemple de quelqu'un qui vous téléphone pour vous demander des conseils. Vous avez le luxe de pouvoir dire que vous pouvez donner des conseils parce que vous ne risquez pas d'être poursuivie.

Dans vos fonctions à la faculté de droit, recevez-vous beaucoup de coups de téléphone de ce genre?

**Mme Downie:** Je reçois effectivement des appels où les gens me décrivent leur situation et me demandent s'ils peuvent interrompre le traitement.

Il y a eu un cas particulièrement poignant qui est arrivé tout de suite après l'affaire *Morrison*. Si vous vous souvenez, il y a eu une ordonnance de non-publication dans cette affaire, si bien que beaucoup de gens ignoraient ce qu'elle avait fait et pensaient que c'était un cas d'abstention de traitement ou d'augmentation croissante d'injections de morphine. Cela a eu un gros effet paralysant.

Quelqu'un au téléphone m'a parlé d'une femme dont on s'occupait à la maison. Elle était branchée sur un respirateur et voulait l'arrêter. La famille le voulait aussi. Ils pensaient tous qu'il était temps d'arrêter. Je leur ai dit que la loi leur permettait de le faire. «Oui, mais personne ne veut le faire», disaient-ils. On m'a demandé pourquoi personne ne voulait arrêter le respirateur chez elle. Ce qui les inquiétait, c'est que le médecin arriverait en voiture, et, comme ils étaient à la campagne, les voisins verraient la voiture du médecin dans l'entrée. Le médecin partirait ensuite, et ils se demandaient combien de temps passerait avant que l'ambulance ou le corbillard arrive. Ils avaient peur d'être inculpés de quelque chose. Je reçois des coups de téléphone comme cela.

C'était un cas de peur paralysante causée par l'affaire *Morrison*, qui portait sur l'interruption et l'abstention. Ils ont dit être prêts à l'amener à l'hôpital et que là ils le feraient, parce qu'ils ne risquaient pas d'être vus.

Dans l'ensemble, le personnel soignant sait que non seulement il peut, mais doit interrompre le traitement de survie que le malade ou son représentant refuse. Par contre les gens sont paralysés par la peur parce que ce n'est pas clair.

Je ne reçois pas beaucoup d'appels, mais suffisamment pour que cela m'ennuie.



Some people will tell me that, since the law is there, we do not need legislation. If you push hard enough, you can find the law, it is clear enough, but I believe that you need the legislation so it is perfectly clear to everyone. Then everyone can relax somewhat about it and turn their attention to caring for their patients instead of worrying about someone knocking on their door.

**The Chairman:** Professor Sneiderman, one section of our report deals with a matter which I have recognized over the years as, perhaps, causing the greatest unease. I am referring to the section which deals with artificial hydration and nutrition.

When talking about the *L. and H.* case, you said that the touching of a patient without consent is assault. May I assume, therefore, that you believe that implanting intravenous lines, or a shunt, if either were the vehicle used to provide nutrition and hydration, without the patient's consent, would also be a form of assault?

**Mr. Sneiderman:** Not necessarily. It would depend upon what the patient had consented to initially. It might also depend upon what the family says about the situation. As you know, there is much that happens in the reality of hospital practice that is not necessarily legally recognized. For example, when a family member is asked to consent to treatment for an adult, unless the family member has been appointed as the patient's legal guardian, or the family member is acting pursuant to a proxy directive, technically speaking that family member has no legal authority to make medical treatment decisions. However, that is simply not the reality of what happens in the real world; and how could it be otherwise?

I do not think we could say that such a patient is being assaulted. I also have serious problems with the Manitoba case which dealt with some very profound issues, and did so in two pages. Interestingly, I heartily agreed with Justice Twaddle when he expressed the view that he simply could not understand why anyone would wish to prolong the life of a patient in a vegetative state. That happens to be my own personal opinion.

**The Chairman:** Let us take a situation in which the patient is conscious and refuses to give permission for his or her own artificial hydration and nutrition, and then, in fact, the lines are connected. Is that assault?

**Mr. Sneiderman:** Yes. If the patient is mentally competent and has said no, then "no" means "no".

**The Chairman:** If a competent patient who has those lines connected wants them disconnected, and that is not done, is that assault?

**Mr. Sneiderman:** If the patient is competent, and there is a treatment in place and the patient has asked that the treatment be stopped, then the treatment must be stopped. You can draw an analogy here to the provisions related to sexual assault in the Criminal Code. "No" means "no", and "yes" now may mean "no" two minutes later. If it is "no" two minutes later, then that is what counts, not the "yes" from two minutes before.

**Senator Beaudoin:** I was absent for a few minutes and when I came back you were talking about the *Latimer* case. I remember we studied that five years ago. I was one of the people who

Des gens me disent que, puisqu'il y a une loi, il n'est pas nécessaire d'en créer une autre. Si l'on fouille assez, on va la trouver, et elle est assez claire, mais je pense qu'il faut une nouvelle loi pour que ce soit limpide pour tout le monde. Les gens pourront ensuite se calmer un peu et mettre leur énergie à s'occuper des malades au lieu de craindre que la police ne frappe à leur porte.

**La présidente:** Professeur Sneiderman, il y a une partie de votre document qui traite d'une question qui cause beaucoup d'embarras, comme je le constate depuis plusieurs années. Je parle de l'hydratation et de l'alimentation artificielles.

Quand vous avez parlé de l'affaire *L. et H.*, vous avez dit que toucher un malade sans son consentement revient à une agression. Dois-je en conclure qu'à votre avis l'insertion d'intraveineuses ou de valves à des fins d'alimentation ou d'hydratation, sans le consentement du malade, serait aussi une forme d'agression?

**M. Sneiderman:** Pas forcément. Cela dépend à quoi le malade avait consenti au début. Cela pourrait dépendre de l'avis de la famille. Comme vous le savez, il se passe beaucoup de choses dans la pratique dans les hôpitaux qui ne sont pas reconnues légalement. Par exemple, lorsqu'un membre de la famille est invité à donner son consentement pour traiter un adulte, à moins qu'un membre de la famille n'ait été désigné tuteur légal du malade ou que le membre de la famille n'agisse en vertu d'une procuration, à strictement parler, le membre de la famille n'a pas légalement le pouvoir de prendre des décisions en matière de traitement médical. Sauf que cela ne correspond pas à la réalité, et, d'ailleurs, comment pourrait-il en être autrement?

On ne pourrait pas dire que ce malade fait l'objet d'une agression. J'ai aussi de graves réserves à propos de la décision manitobaine qui a soulevé des questions très profondes en deux pages à peine. Chose intéressante, je suis tout à fait de l'avis du juge Twaddle, qui dit ne pas comprendre pourquoi quiconque voudrait protéger la vie d'un malade en état végétatif. Il se trouve que c'est mon avis également.

**La présidente:** Prenons le cas du malade qui est lucide et qui refuse d'être alimenté et hydraté artificiellement et à qui on insère quand même les intraveineuses. Est-ce une agression?

**M. Sneiderman:** Oui. Si le malade jouit de ses facultés et a refusé, alors «non» signifie «non».

**La présidente:** Si le malade est sous perfusion et veut que les intraveineuses soient enlevées et qu'on ne lui obéisse pas, est-ce une agression?

**M. Sneiderman:** Si le malade est lucide, qu'un traitement est en cours et qu'il demande que le traitement soit interrompu, alors il doit l'être. Vous pouvez établir une analogie ici avec les dispositions sur l'agression sexuelle dans le Code criminel. «Non» signifie «non», et «oui» maintenant peut signifier «non» deux minutes plus tard. Si c'est «non» deux minutes plus tard, c'est ce qui compte, et non pas le «oui» de deux minutes plus tôt.

**Le sénateur Beaudoin:** J'ai été absent pendant quelques instants et à mon retour vous parliez de l'affaire *Latimer*. Je me souviens que nous avons étudié le cas il y a cinq ans. Je suis l'un

suggested we study that case. I am looking at the recommendations in the report of the committee, page 88.

Did you consider, Madam Chairman, that it was really a study that was conducted on this and, if so, what was the result of the study? Were the findings unanimously agreed to by the committee members?

**The Chairman:** No.

**Senator Corbin:** What issue are we discussing here?

**Senator Beaudoin:** Compassionate homicide.

**The Chairman:** What is clear is our recommendation that a third category of murder be created. Our recommendation was that the individual still be charged with murder, go through all of the legal processes, and if he or she were convicted of murder, the judge, in considering sentence, would have the option of imposing a sentence applicable to a third category of murder charge as opposed to a sentence which would be appropriate in a first or second degree murder charge which have mandatory life sentences with 10 and 25 years before eligibility for parole.

It is fair to say, Senator Beaudoin, that much of our interest in that charge came from what we knew about the *Latimer* case. To be fair, we made no final judgment on *Latimer* because we knew it would not be over by the time we came out with our report. That was only the end of his first trial. We were then quite sure there would be a second trial. That, of course, has happened, and now there is an appeal before the Supreme Court of Canada. On the first appeal to the Supreme Court of Canada, the court ordered a new trial.

**Senator Beaudoin:** That is exactly, as I remember it. This question, of course, is very important, but we must wait for a decision of the Supreme Court.

Is discussion of this subject now part of our mandate? It has been dealt with in the discussion of nonvoluntary euthanasia.

**The Chairman:** It is part of our mandate to study the issue of a third category of murder charge, because that was one of the issues on which we were unanimous. Our mandate is to study all recommendations of the committee on which we were unanimous.

**Senator Corbin:** When you say "we", you mean the members of the committee "at that time". We now have new committee members.

**The Chairman:** That is right.

**Senator Beaudoin:** I am not so sure that we were unanimous on that. I agree with what we have said, but were committee members unanimous on this?

**Mr. Sniderman:** It says "the committee recommends" and there are no dissenting voices noted on page 88.

**The Chairman:** The committee recommended that the Criminal Code be amended.

de ceux qui avaient suggéré de l'étudier. Je me reporte aux recommandations du rapport du comité, à la page 91.

Estimez-vous, madame la présidente, qu'il s'agit bien d'une étude qui a été réalisée sur la question, et, dans l'affirmative, quel est le résultat de cette étude? Les membres du comité ont-ils adopté à l'unanimité les conclusions?

**La présidente:** Non.

**Le sénateur Corbin:** De quelle question discutons-nous ici?

**Le sénateur Beaudoin:** L'homicide par compassion.

**La présidente:** Ce qui est clair, c'est notre recommandation selon laquelle une troisième catégorie de meurtre devrait être créée. Nous avons recommandé que l'individu soit inculpé de meurtre, suive la procédure, et que sur déclaration de culpabilité le juge puisse imposer une peine applicable à cette troisième catégorie de meurtre, par opposition à une peine pour meurtre au premier ou au deuxième degré, et qui comporte la réclusion obligatoire à perpétuité avec possibilité de libération conditionnelle dans 10 ou 25 ans.

On peut dire honnêtement, sénateur Beaudoin, que notre intérêt pour ce type d'inculpation était attribuable à ce que nous savions de l'affaire *Latimer*. Pour être juste, il faut dire que nous n'avons pas porté de jugement définitif sur l'affaire *Latimer* parce que nous savions qu'elle n'allait pas être réglée avant la publication de notre rapport. Nous étions à la fin de son premier procès. Nous étions alors convaincus qu'il y en aurait un deuxième. C'est évidemment ce qui s'est produit, et aujourd'hui la Cour suprême est saisie d'un appel. Lors du premier appel à la Cour suprême, celle-ci a ordonné un nouveau procès.

**Le sénateur Beaudoin:** Cela correspond exactement à mes souvenirs. Il s'agit là d'une question très importante, mais nous devons attendre la décision de la Cour suprême.

L'examen de cette question fait-il maintenant partie de notre mandat? On en a traité lorsque l'on a examiné celle de l'euthanasie non volontaire.

**La présidente:** Nous sommes mandatés pour examiner la question d'une inculpation pour une troisième catégorie de meurtre, parce que c'est l'un des points qui ont fait l'unanimité. Notre mandat est d'étudier toutes les recommandations du comité qui ont été adoptées à l'unanimité.

**Le sénateur Corbin:** Quand vous dites «nous», parlez-vous des membres du comité à ce moment-là? Le comité compte aujourd'hui de nouveaux membres.

**La présidente:** Effectivement.

**Le sénateur Beaudoin:** Je ne suis pas certain qu'il y avait unanimité sur ce point. Je suis d'accord avec ce que nous avons dit, mais les membres du comité étaient-ils unanimes sur ce point?

**M. Sniderman:** Le texte dit «le comité recommande», et il n'y a pas de dissidence relevée à la page 91.

**La présidente:** Le comité recommande que le Code criminel soit modifié.



If you look under "voluntary euthanasia" and under "nonvoluntary euthanasia" you will see we had a majority and a minority vote in both instances. However, in this instance you will see at the top, Senator Beaudoin, the recommendation was unanimously adopted.

**Senator Beaudoin:** That is not a problem for me because I agree with that decision. Do you consider that it is part of our mandate now?

**The Chairman:** Yes, I do indeed.

**Senator Beaudoin:** I am of the opinion that we should amend the Criminal Code in a case like this. However, there is no easy answer.

You said that what happened in the *Latimer* case should not happen again because the sentence was much too high. Is that the case?

**Mr. Sniderman:** That is my opinion.

**Senator Beaudoin:** That is your view.

**The Chairman:** To be fair, Professor Sniderman also gave us an alternative related to the creation of a third category of murder, and I know we will want to consider that. He said that, instead of dealing with creating a third category, we should perhaps be reviewing the whole issue of presumptive sentencing. Have I understood you correctly, Professor Sniderman?

**Senator Beaudoin:** Would you summarize that for me?

**Mr. Sniderman:** First, the committee's recommendations focused specifically on mercy killing; either it is manslaughter or it is a different category of murder. Focusing upon mandatory minimum sentencing for murder, we are not directly dealing with mercy killing because there are other scenarios. For example, the battered women syndrome, where we might say that it is not really self-defence and it is not provocation. There is the defence of provocation. Perhaps, if we did not have mandatory minimum sentencing, we could do away with the myth — which I believe is a myth — that there are people who commit murder while drunk and the law accepts that there is not the *mens rea* for murder. They are all cases in which the victim is someone with whom the accused was angry. It is never a case where someone who gets so drunk that he kills his best friend because he did not know what he was doing. Therefore, if we did not have an inflexible rule we would not need to worry so much about the label that is attached to the act. We could then turn to the punishment. We could simply amend the Criminal Code to provide that the mandatory minimum sentences remain in place. However, if the defence wishes to contest the mandatory minimum sentence after conviction, then it would be for the defence to prove why the mandatory minimum should not apply in that particular case. Perhaps we might even go to a burden of proof that goes somewhat beyond the civil burden of proof.

There is a category of proof in the United States, concerning clear and convincing evidence, that applies in some of the so-called "right to die" cases. It is a burden of proof that is

Si vous regardez sous «euthanasie volontaire» et sous «euthanasie non volontaire», vous verrez que dans les deux cas il y a une majorité et une minorité de voix. Dans ce cas-ci, en haut, sénateur Beaudoin, vous verrez que la recommandation a été adoptée à l'unanimité.

**Le sénateur Beaudoin:** Cela ne me cause pas de difficulté parce que je suis d'accord avec cette décision. Estimez-vous que cela fait partie de notre mandat actuel?

**La présidente:** Oui, tout à fait.

**Le sénateur Beaudoin:** Je suis d'avis qu'il y a lieu de modifier le Code criminel dans un cas comme celui-ci. Toutefois, il n'y a pas de réponse toute faite.

Vous avez dit que ce qui s'est passé dans l'affaire *Latimer* ne devrait pas se reproduire parce que la peine était beaucoup trop lourde. C'est bien le cas?

**M. Sniderman:** C'est mon avis.

**Le sénateur Beaudoin:** C'est votre avis.

**La présidente:** Pour être juste, le professeur Sniderman nous a proposé une autre solution que la création d'une troisième catégorie de meurtre, et je sais que nous voudrions l'examiner. Il a dit que nous devrions peut-être à la place examiner toute la question de la présomption légale de peine. Vous ai-je bien compris, professeur Sniderman?

**Le sénateur Beaudoin:** Pourriez-vous me résumer cela?

**M. Sniderman:** Premièrement, les recommandations du comité portaient expressément sur le meurtre par compassion; ou bien il s'agit d'homicide involontaire ou d'une autre catégorie de meurtre. S'agissant de la peine minimale obligatoire en cas de meurtre, nous ne traitons pas directement du meurtre par compassion parce qu'il y a d'autres possibilités. Par exemple, celui du syndrome de la femme battue où l'on peut dire qu'il ne s'agit pas vraiment d'autodéfense ni de provocation. Il y a la défense de l'agression provoquée. Peut-être, s'il n'y avait pas de peine minimale obligatoire, pourrions-nous faire disparaître le mythe — car j'estime que c'en est un — selon lequel il y a des gens qui commettent un meurtre en état d'ébriété, et la loi accepte qu'il n'y a pas d'intention criminelle. Il s'agit dans tous les cas de situations où la victime est quelqu'un contre qui l'accusé était en colère. Ce n'est jamais le cas de quelqu'un qui est ivre au point de tuer son meilleur ami parce qu'il ignorait ce qu'il faisait. Cela signifie que s'il n'y avait pas de règle inflexible nous n'aurions pas à nous préoccuper à ce point du nom que l'on donne à l'acte. Nous pourrions ensuite nous pencher sur le châtiment. Nous pourrions simplement modifier le Code criminel pour faire en sorte que les peines minimums obligatoires continuent d'exister. Toutefois, si la défense souhaite contester cette peine minimum obligatoire après une déclaration de culpabilité, ce serait à la défense de prouver pourquoi le minimum obligatoire ne devrait pas s'appliquer en l'espèce. Nous pourrions peut-être même accepter un fardeau de la preuve un peu plus lourd que celui qui existe en matière civile.

Il y a une catégorie de preuve aux États-Unis, relative à la preuve claire et convaincante, qui s'applique dans certains cas de ce que l'on appelle le droit de mourir. Ce fardeau de la preuve se

somewhere between the civil burden of proof, preponderance of evidence, and the criminal law burden of proof beyond a reasonable doubt. If the defence were able to satisfy that burden in a particular case, then we would be able to remove the shackles from the judge's hands. The judge still may impose a nine-year or an eight-year sentence, or the judge might decide that it is an appropriate case for no incarceration. That is my proposal.

**Senator Beaudoin:** I want to be very clear cut in law. Our discussion at that time — and, it was at the end of our discussion — concerned a third-degree murder charge. We used that expression, but it was still a murder.

**Mr. Sniderman:** Right.

**Senator Beaudoin:** We did not have time to consider the matter more deeply than that. As the chair said, the *Latimer* case was before the courts. A murder such as one is certainly not an ordinary murder. Our concern was related to the remedy — that is, the sentence — rather than to the crime itself. Of course it is a murder, but it does not make sense to punish that person in the same way as we would punish certain other persons in some other cases. This is exactly what we said.

You have offered us another alternative, namely, that it not be considered murder.

**Mr. Sniderman:** No. The crime remains the same.

**Senator Beaudoin:** The crime remains?

**Mr. Sniderman:** Yes. What changes is the options at sentencing. In other words, the crime remains the same, whether first-degree or second-degree murder. The *Latimer* case was a case of first-degree murder. I still do not understand why the trial judge at the first trial gave the jury the option of second-degree murder. It should have been either first-degree murder or nothing. If ever there was a planned and deliberate killing, that was such a killing. The label remains the same. It is still murder.

We then move to sentencing. Now a judge's hands are shackled. The judge must hand down a sentence of life imprisonment with parole eligibility set somewhere between 10 and 25 years. I would suggest that the defence be given the opportunity to satisfy the sentencing judge that, in the particular case, there are compelling circumstances and the mandatory minimum provision should be waived. As you know, for a second conviction of impaired driving, there is a mandatory sentence of 14 days; committing an offence with a firearm carries a mandatory term of one year. However, for the vast majority of Criminal Code offences, there is no mandatory minimum sentence. What judges do all the time — and what they are trained to do — is take into consideration factors that are not relevant to the question of guilt or innocence. Those factors can be determinative to the question: What is the appropriate punishment in the particular case?

**Senator Beaudoin:** Still, the debate remains only on the punishment.

**Mr. Sniderman:** That is right.

situe entre le fardeau en matière civile, la prépondérance de la preuve, et le fardeau en matière criminelle, celui de preuve au-delà de tout doute. Si la défense arrivait à répondre aux critères du fardeau dans un cas particulier, nous pourrions ensuite délier les mains du juge. Celui-ci pourrait toujours imposer une peine de neuf ou huit ans ou statuer que l'incarcération n'est pas appropriée. C'est ma proposition.

**Le sénateur Beaudoin:** Je veux que ce soit très clair en droit. Notre discussion à ce moment-là — et c'était à la fin des discussions — portait sur l'inculpation de meurtre au troisième degré. Nous utilisons cette expression, mais cela reste un meurtre.

**M. Sniderman:** Oui.

**Le sénateur Beaudoin:** Nous n'avons pas eu le temps d'examiner la chose plus en profondeur. Comme la présidente l'a dit, l'affaire *Latimer* était devant les tribunaux. Un meurtre comme celui-là n'est pas un meurtre ordinaire. Ce qui nous préoccupait, c'était la sanction — la peine — plutôt que le crime proprement dit. Bien sûr il s'agit d'un meurtre, mais il n'est pas sensé de punir son auteur de la même façon que d'autres meurtriers. C'est exactement ce que nous avons dit.

Vous nous offrez une autre possibilité, à savoir que cela ne serait pas considéré comme un meurtre.

**M. Sniderman:** Non. Le crime reste le même.

**Le sénateur Beaudoin:** Le crime reste le même?

**M. Sniderman:** Oui. Ce qui change, ce sont les options qui s'offrent au moment d'imposer la peine. Autrement dit, le crime reste le même, meurtre au premier ou au deuxième degré. Dans l'affaire *Latimer*, il s'agissait d'un meurtre au premier degré. Je ne comprends toujours pas pourquoi le juge de première instance a donné au jury l'option de retenir l'accusation de meurtre au deuxième degré. Cela aurait dû être ou bien le meurtre au premier degré ou rien du tout. Et si jamais il y a eu une suppression délibérée de la vie, c'est bien dans ce cas. L'appellation reste la même. C'est toujours un meurtre.

Ensuite nous passons à la peine. Ici, le juge a les mains liées. Il doit imposer une peine de prison à perpétuité avec une admissibilité à la libération conditionnelle qui se situe entre 10 et 25 ans. Je propose que la défense ait la possibilité de persuader le juge qui prononce la peine que, en l'espèce, il existe des circonstances déterminantes et que la peine minimum obligatoire ne doit pas s'appliquer. Comme vous le savez, dans le cas d'une deuxième condamnation de conduite avec facultés affaiblies, la peine obligatoire est 14 jours; commettre une infraction avec une arme à feu entraîne un an d'emprisonnement obligatoire. Toutefois, pour l'immense majorité des infractions au Code criminel, il n'y a pas de peine minimum obligatoire. Ce que les juges font tout le temps — c'est à cela qu'ils sont formés — c'est tenir compte de facteurs qui n'interviennent pas dans la détermination de la culpabilité ou de l'innocence. Il s'agit de facteurs relatifs à la question de savoir quel est le châtiment approprié en l'espèce.

**Le sénateur Beaudoin:** Le débat qui reste porte donc uniquement sur le châtiment.

**M. Sniderman:** Précisément.



**Senator Beaudoin:** That is very different from any other solution. What the remedy should be is the real question.

**Mr. Sneiderman:** It would achieve the same result in this kind of case, as would the enactment of either of the committee's recommendations, whether it is manslaughter or a third-degree murder charge. It simply does it a different way.

I wrote an article proposing a mercy killing defence that was published in the *Health Law Journal*. It was about the *Latimer* case. In the recent article that I wrote, I made no reference to a mercy killing defence, I referred to mandatory minimum sentencing because I had come to the conclusion that the mercy killing route would simply not happen. To me, it is not politically feasible.

**Senator Beaudoin:** I raised that question because I do not think it should have been dealt with at that section of the report. It does not really come under euthanasia.

**The Chairman:** You are quite right, Senator Beaudoin. It probably should not have been in that section of the report.

**Senator Beaudoin:** Logically, it should not be there, in my opinion.

**The Chairman:** Yes, you are right.

**Senator Roche:** Did you say a moment ago, Madam Chairman, that this committee will examine the recommendations that were unanimous and not those that were not unanimous?

**The Chairman:** Yes.

**Senator Roche:** Is that in the terms of reference?

**The Chairman:** Yes, it is. That is why we made it very clear that we would not be debating the issues of assisted suicide and euthanasia. We will deal with all the other issues because we were unanimous on the all the others. However, we were not unanimous on our final conclusions about euthanasia and assisted suicide. Interestingly, when we started writing our report, the issues of euthanasia and assisted suicide were our main focus. However, as we heard from our witnesses, it became clear that they wanted to debate many other issues with us, including palliative care, the withholding and withdrawal of life support treatment, and so on. The report became much broader than what we had originally intended the report to be. We felt it was necessary to address the issues that were of clear concern to the Canadians who appeared before the committee.

**Senator Roche:** Is it possible to have a firewall between these issues? Is there not an interconnection between palliative care and euthanasia? How will you limit the discussion?

**The Chairman:** Clearly, there is an interconnection. We are telling the witnesses — and, we told the witnesses who appeared before us today the same thing — that we want them to focus on the unanimous recommendations of the committee because we want to examine where the government has gone on those unanimous recommendations. We felt that it was relatively easy for the government to address those issues, since they had a

**Le sénateur Beaudoin:** Cela est très différent des autres solutions. La véritable question, ce devrait être la sanction.

**M. Sneiderman:** On arriverait au même résultat ici, comme ce serait le cas si on acceptait l'une ou l'autre des recommandations du comité, qu'il s'agisse d'une inculpation pour homicide involontaire ou pour meurtre au troisième degré. On y arrive autrement, c'est tout.

J'ai rédigé un article qui proposait la défense du meurtre par compassion. L'article portait sur l'affaire *Latimer* et a été publié dans *Health Law Journal*. Dans un article récent, je ne parlais plus de défense du meurtre par compassion; je parlais plutôt de peine minimale obligatoire parce que je suis arrivé à la conclusion que l'option du meurtre par compassion n'est pas réalisable. Pour moi, ce n'est pas politiquement faisable.

**Le sénateur Beaudoin:** Si je vous ai posé la question, c'est qu'à mon avis on n'aurait pas dû en parler dans cette partie du rapport. Cela ne devrait pas vraiment se trouver sous l'euthanasie.

**La présidente:** Vous avez tout à fait raison, sénateur Beaudoin. Cela n'aurait pas dû figurer dans cette partie du rapport.

**Le sénateur Beaudoin:** Logiquement, cela ne devrait pas être là.

**La présidente:** Vous avez raison.

**Le sénateur Roche:** Madame la présidente, n'avez-vous pas dit il y a un instant que le comité devait examiner uniquement les recommandations adoptées à l'unanimité?

**La présidente:** Oui.

**Le sénateur Roche:** Cela figure-t-il dans le mandat?

**La présidente:** Oui; c'est pourquoi nous avons bien dit que nous ne discuterions pas des questions de l'aide au suicide et de l'euthanasie. Nous allons aborder toutes les autres questions parce qu'elles ont toutes fait l'unanimité. Toutefois, il n'y a pas eu d'unanimité dans nos conclusions à propos de l'euthanasie et de l'aide au suicide. Chose intéressante, quand nous avons commencé à rédiger notre rapport, l'euthanasie et l'aide au suicide étaient nos principaux points à l'étude. Toutefois, au fur et à mesure que nous avons entendu des témoins, il est apparu que nous voulions débattre de beaucoup d'autres questions, y compris les soins palliatifs, l'interruption et l'abstention de traitement de survie, et cetera. Le rapport a pris une ampleur beaucoup plus grande que ce qui avait été prévu. Nous avons décidé de traiter de questions qui de toute évidence préoccupaient les citoyens qui ont comparu devant le comité.

**Le sénateur Roche:** Est-il possible d'ériger un pare-feu entre ces deux questions? N'y a-t-il pas un lien à faire entre soins palliatifs et euthanasie? Comment pouvez-vous limiter la discussion?

**La présidente:** Il y a manifestement un lien entre les deux. Nous disons aux témoins — et c'est ce que nous avons dit aux témoins que nous entendons aujourd'hui — que nous les invitons à se concentrer sur les recommandations qui ont été faites à l'unanimité par le comité, mais que nous voulons aussi chercher à voir ce que le gouvernement a fait de ces recommandations unanimes. Nous étions d'avis qu'il serait assez facile pour le

unanimous report. We always recognized that it would be much more difficult to deal with other issues. After all, the Supreme Court of Canada, in *Rodriguez*, was not unanimous. By the slightest coincidence, the split on that decision was exactly the same percentage as the split in the vote on the adoption of the Senate report.

**Senator Roche:** Finally then, the work of this committee is to prod the government to implement those recommendations that were unanimous in the report, as distinct from our further reflection on disputed and controversial questions, is that correct?

**The Chairman:** That is right. To be fair, it is for us to also conduct a review of our unanimous recommendations. Perhaps we have changed our minds on those unanimous recommendations. We had an interesting dialogue today on the number 3 recommendation. We may not reach the same conclusions as the original committee with respect to how to deal with a mercy killing charge after hearing the testimony today from Professor Sneiderman that there might be another way to deal with this issue. Maybe we can provide the government with two options by which they might want to proceed.

The mandatory life sentence of 25 years on first-degree murder was proclaimed when we struck down capital punishment. I am not sure the government will move on that one, but that is my personal opinion.

**Senator Corbin:** Has the press release gone out?

**The Chairman:** Yes, the press release went out today. The press release is very clear that the committee will only be considering the unanimous recommendations.

On behalf of the committee, I would thank Professor Downie who came from Halifax and Professor Sneiderman who came from Winnipeg. I apologize for the weather conditions here in capital.

The committee adjourned.

gouvernement de s'attaquer à ces questions-là, puisqu'elles avaient fait l'objet d'un rapport unanime. Nous sommes conscients toutefois qu'il lui serait bien plus difficile de s'attaquer à d'autres questions. Après tout, la décision de la Cour suprême du Canada dans l'affaire *Rodriguez* n'était pas unanime. Par le plus pur des hasards, il se trouve que le partage des voix y était exactement le même que pour l'adoption du rapport du Sénat.

**Le sénateur Roche:** Ainsi, le travail de notre comité consiste à aiguillonner le gouvernement pour qu'il donne suite aux recommandations de notre rapport qui ont reçu un appui unanime, par opposition aux questions plus controversées qui méritent une plus ample réflexion, c'est bien cela?

**La présidente:** C'est bien cela. En toute justice, il nous appartient aussi de revoir nos recommandations unanimes. Nous avons peut-être changé d'avis depuis. Nous avons eu un dialogue intéressant aujourd'hui sur la recommandation numéro 3. Nous n'arrivons peut-être pas aux mêmes conclusions que le premier comité quant à la suite à donner à une accusation de meurtre par compassion après avoir entendu le témoignage que nous a livré aujourd'hui le professeur Sneiderman, qui nous laissait entendre qu'il pourrait y avoir une autre façon de s'y prendre. Nous pourrions peut-être proposer au gouvernement deux scénarios possibles.

L'emprisonnement à perpétuité obligatoire de 25 ans pour quiconque est condamné de meurtre au premier degré a été proclamé quand nous avons invalidé la peine capitale. Je ne suis pas sûre que le gouvernement veuille modifier cette disposition, mais c'est là mon avis personnel.

**Le sénateur Corbin:** Le communiqué de presse a-t-il déjà été publié?

**La présidente:** Oui, il a été publié aujourd'hui. Nous disons très clairement dans le communiqué de presse que le comité ne va étudier que les recommandations unanimes.

Au nom du comité, je tiens à remercier Mme Downie, qui est venue de Halifax, et le professeur Sneiderman, qui est venu de Winnipeg. Je vous présente nos excuses pour le mauvais temps qui sévit dans la capitale.

La séance est levée.





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WITNESSES—TÉMOINS

*From Dalhousie University:*

Professor Jocelyn Downie, Health Law Institute.

*From the University of Manitoba:*

Professor Barney Sneiderman, Faculty of Law.

*De l'Université Dalhousie:*

Jocelyn Downie, professeure, Health Law Institute.

*De l'Université du Manitoba:*

Barney Sneiderman, professeur, faculté de droit.

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Second Session  
Thirty-sixth Parliament, 1999-2000

Deuxième session de la  
trente-sixième législature, 1999-2000

## SENATE OF CANADA

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## SÉNAT DU CANADA

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*Standing Senate Committee on Social Affairs,  
Science and Technology*

*Comité sénatorial permanent des affaires sociales,  
des sciences et de la technologie*

*Proceedings of the Subcommittee to*

*Délibérations du sous-comité de*

# Update “Of Life and Death”

# Mise à jour de «De la vie et de la mort»

*Chair:*  
The Honourable SHARON CARSTAIRS

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*Présidente:*  
L'honorable SHARON CARSTAIRS

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Tuesday, February 15, 2000

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Le mardi 15 février 2000

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Issue No. 2

Fascicule n° 2

### Second meeting on:

### Deuxième réunion concernant:

Examination of the developments since the tabling in  
June 1995 of the final report of the Special Senate  
Committee on Euthanasia and Assisted Suicide,  
entitled: “Of Life and Death”

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L'étude des faits nouveaux survenus depuis le dépôt,  
en juin 1995, du rapport final du comité sénatorial  
spécial sur l'euthanasie et l'aide au suicide intitulé:  
«De la vie et de la mort»

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WITNESSES:  
(See back cover)

TÉMOINS:  
(Voir à l'endos)



THE SUBCOMMITTEE TO UPDATE  
“OF LIFE AND DEATH”

The Honourable Sharon Carstairs, *Chair*

The Honourable Gérard-A. Beaudoin, *Deputy Chair*

and

The Honourable Senators:

\* Boudreau, P.C.  
(or Hays)  
Corbin  
Keon

\* Lynch-Staunton  
(or Kinsella)  
Pépin

\* *Ex Officio Members*

(Quorum 3)

LE SOUS-COMITÉ DE MISE À JOUR DE  
«DE LA VIE ET DE LA MORT»

*Présidente:* L'honorable Sharon Carstairs

*Vice-président:* L'honorable Gérard-A. Beaudoin

et

Les honorables sénateurs:

\* Boudreau, c.p.  
(ou Hays)  
Corbin  
Keon

\* Lynch-Staunton  
(ou Kinsella)  
Pépin

\* *Membres d'office*

(Quorum 3)

**MINUTES OF PROCEEDINGS**

OTTAWA, Tuesday, February 15, 2000

(4)

*[English]*

The Subcommittee to update "Of Life and Death" met this day in room 257, East Block, at 9:05 a.m., the Honourable Sharon Carstairs, Chair, presiding.

*Members of the subcommittee present:* The Honourable Senators Beaudoin, Carstairs, Corbin and Pépin (4).

*Other Senator present:* The Honourable Senator Roche (1).

*In attendance:* Mollie Dunsmuir and Nancy Miller-Chénier, Research Officers, Research Branch, Library of Parliament.

*Also in attendance:* The official reporters of the Senate.

Pursuant to its Order of Reference adopted in the Standing Senate Committee on Social Affairs, Science and Technology on Monday, November 29, 1999, the subcommittee continued its examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death". (*For full text of Order of Reference please refer to Issue No. 1*)

**WITNESSES:**

*From the Canadian Palliative Care Association and the Association québécoise de soins palliatifs:*

Dr. Bernard Lapointe, President.

*From the College of Family Physicians of Canada:*

Dr. Richard MacLachlan, Head, Faculty of Medicine, Dalhousie University.

The Chair made an opening statement.

The Honourable Senator Roche asked the Chair for clarification regarding the terms of reference of the Subcommittee.

Dr. Lapointe made a statement.

Dr. MacLachlan made a statement.

The witnesses answered questions.

At 10:50 a.m., the subcommittee adjourned to the call of the Chair.

**ATTEST:**

**PROCÈS-VERBAL**

OTTAWA, le mardi 15 février 2000

(4)

*[Traduction]*

Le sous-comité de mise à jour de «De la vie et de la mort» se réunit aujourd'hui à 9 h 05, dans la pièce 257 de l'édifice de l'Est, sous la présidence de l'honorable Sharon Carstairs (*présidente*).

*Membres du sous-comité présents:* Les honorables sénateurs Beaudoin, Carstairs, Corbin et Pépin (4).

*Autres sénateur présent:* L'honorable sénateur Roche (1).

*Également présentes:* Mollie Dunsmuir et Nancy Miller-Chénier, attachées de recherche, Direction de la recherche parlementaire, Bibliothèque du Parlement.

*Aussi présents:* Les sténographes officiels du Sénat.

Conformément à l'ordre de renvoi adopté par le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie le lundi 29 novembre 1999, le sous-comité poursuit son étude des faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort». (*L'ordre de renvoi figure dans le fascicule n° 1.*)

**TÉMOINS:**

*De l'Association canadienne des soins palliatifs et de l'Association québécoise de soins palliatifs:*

M. Bernard Lapointe, président.

*Du Collège des médecins de famille du Canada:*

M. Richard MacLachlan, directeur, faculté de médecine, Université Dalhousie.

La présidente fait une déclaration.

L'honorable sénateur Roche demande à la présidente de clarifier le mandat du sous-comité.

M. Lapointe fait une déclaration.

M. MacLachlan fait une déclaration.

Les témoins répondent aux questions.

À 10 h 50, le sous-comité suspend ses travaux jusqu'à nouvelle convocation de la présidente.

**ATTESTÉ:**

*La greffière du sous-comité,*

Heather Lank

*Clerk of the Subcommittee*



## EVIDENCE

OTTAWA, Tuesday, February 15, 2000

The Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 9:00 a.m. to examine the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death."

**Senator Sharon Carstairs** (*Chairman*) in the Chair.

[*English*]

**The Chairman:** Good morning, honourable senators, witnesses and those in the viewing audience. Today is the second day of hearings under our mandate to update the unanimous recommendations of the 1995 Special Senate Committee Report on Euthanasia and Assisted Suicide entitled "Of Life and Death."

I would remind honourable senators and witnesses that this committee is not reopening the debate on assisted suicide and euthanasia; rather, it is dealing strictly with the areas of the report where the original committee made unanimous recommendations. I would ask everyone to bear this in mind as we proceed through the hearings.

Today we have two witnesses. I welcome both of you. I would ask you to try to stay within the 15-minute time frame for your opening remarks; however, I do not have a stopwatch.

Before we hear our witnesses, Senator Roche has a comment.

**Senator Roche:** This comment will be brief and is not intended to be argumentative. It concerns the point I raised yesterday about the scope of the work of this committee with respect to the differentiation between the majority and minority points raised in the report.

I did not have the terms of reference before me yesterday to refresh my memory about the second point therein. While the first point is that the committee will study the unanimous recommendations of the committee of 1995, the second point is that it would look at all aspects, and I had that in my mind as to how the committee would differentiate.

My interpretation of the testimony of the witnesses yesterday — though they had a right to express their views — is that they were moving into areas that had previously divided the committee by looking at ways of enlarging the manner in which people can be assisted in the decisions they must take.

As I said, it is not my intention to argue that point here. You may wish to reserve comment on this and give me your advice at another time. That is perfectly fine with me.

I do not have it perfectly clear in my head as to the limitation of testimony. If witnesses are in a sense leading the members of the committee in their testimony, as I thought they were doing yesterday, then it seems to me that the committee, in looking at

## TÉMOIGNAGES

OTTAWA, le mardi 15 février 2000

Le sous-comité de mise à jour de «De la vie et de la mort» du comité sénatorial permanent des affaires sociales, des sciences et de la technologie se réunit aujourd'hui à 9 h 05 pour examiner les faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé «De la vie et de la mort».

**Le sénateur Sharon Carstairs** (*présidente*) occupe le fauteuil.

[*Traduction*]

**La présidente:** Bonjour, honorables sénateurs, messieurs les témoins et membres du public qui nous écoutez à la télévision. Nous en sommes à notre deuxième jour d'audience, en vertu de notre mandat de mettre à jour les recommandations unanimes contenues dans le rapport de 1995 du comité sénatorial spécial sur l'euthanasie et l'aide au suicide, qui s'intitulait: «De la vie et de la mort».

Je rappelle à mes collègues ainsi qu'aux témoins que le présent comité n'a pas pour mandat de rouvrir le débat sur l'aide au suicide et l'euthanasie. Il doit plutôt traiter uniquement des points du rapport pour lesquels le comité initial a établi des recommandations unanimes. Je vous demanderais de ne pas perdre de vue ce fait au cours des audiences.

Nous avons aujourd'hui deux témoins. Je vous souhaite la bienvenue. Je vous prie de respecter la limite de 15 minutes qui vous est impartie pour vos remarques liminaires. Rassurez-vous, cependant, ce n'est pas 15 minutes montre en main.

Avant d'entendre nos témoins, le sénateur Roche voudrait y aller de quelques commentaires.

**Le sénateur Roche:** Je serai bref, et je ne désire pas lancer un débat. Ce que j'ai à dire concerne le point que j'ai soulevé hier, au sujet de la portée des travaux de notre comité et de la distinction à faire entre les aspects majoritaires et minoritaires du rapport.

Je n'avais pas sous les yeux le mandat, hier, pour me rafraîchir la mémoire au sujet du second point. Le premier point prévoit que le comité doit étudier les recommandations unanimes du comité de 1995, mais d'après le second, il doit également étudier tous les aspects, et je me demandais comment le comité allait établir une différence.

Mon interprétation de ce qu'ont dit hier les témoins — qui avaient parfaitement le droit d'exprimer leurs opinions —, c'est qu'ils entraient dans des domaines qui ont auparavant divisé le comité, en cherchant à déterminer des moyens par lesquels on pourrait étendre la façon dont on peut aider les gens à prendre leurs décisions.

Comme je l'ai dit, je n'ai pas l'intention de lancer un débat. Vous pouvez choisir de réserver vos commentaires sur le sujet pour m'en faire part plus tard. Cela me convient parfaitement.

Les limites à imposer aux témoins ne sont pas parfaitement claires dans mon esprit. Si, en quelque sorte, les témoins orientent les travaux du comité, comme ils l'ont fait, d'après moi, hier, il me semble que mes collègues, quand ils vont se pencher sur ce

what it is going to discuss and hence recommend, would have difficulty seeing that fire wall. It would be difficult to detect a sharp distinction between what the minority was advocating with respect to assisted suicide and voluntary euthanasia and what the committee as a whole did recommend.

There is ambiguity in my mind. I wanted to register that with you and seek your guidance with respect to it. Is there any actual limitation on what the committee will examine, particularly in terms of point 2 of the terms of reference?

**The Chairman:** All I can say is that, according to the wording in the *Journals of the Senate*, point 2 refers to developments in Canada respecting the issues dealt with in the report. We can certainly look at some of the issues dealt with in the report, but I think that the overarching responsibility of this committee is the progress on the implementation of the unanimous recommendations made in the report. When we write our final report, that will certainly be the focus to which I ask the people at this table to begin the drafting process. I think that is where the focus should be.

Having said that, there are developments that have happened in Canada that will make addenda to the material, but we will make no judgment on those addenda. For example, if in fact there have been some legal cases that would add to the body of knowledge, we should make reference to those legal cases. However, I do not think we should make any judgment on those legal cases.

**Senator Roche:** I found your comments most helpful. I should also like to reregister my concern. Perhaps if there were some way in which we could discuss this question at an appropriate moment, I would find that helpful.

**The Chairman:** We will certainly discuss it when we are going to give instructions to those who will be drafting the original report.

We will begin now with Dr. Lapointe.

[Translation]

**Dr. Bernard Lapointe, President of the Canadian Palliative Care Association and the Association québécoise des soins palliatifs:** Madam Chair, the position of the Canadian Palliative Care Association was presented to you six years ago by Dr. Ina Cummings, who was the association's president at the time. Our position on euthanasia and assisted suicide has not changed since that time.

This morning, I will specifically focus my comments on your report's recommendations on the development of palliative care.

I would like to say, on behalf of the Canadian Association, that we appreciate your courage and leadership in dealing with the difficult and painful questions in your 1995 report. I am appreciative of the opportunity to meet with and report to you this morning on the evolution of palliative care.

As you noted in your report, there are many reasons why a person may request assisted suicide or euthanasia: unrelieved pain or other physical symptoms, depression and psychological

qu'ils vont discuter et, par conséquent, recommander, auraient de la difficulté à voir cet écueil. Il serait difficile d'établir une distinction claire entre ce que la minorité recommandait au sujet de l'aide au suicide ou de l'euthanasie volontaire et ce que le comité dans son ensemble a recommandé.

Il y a là une ambiguïté, à mon avis. Je voulais vous en faire part et vous demander ce que vous en pensez. Y a-t-il des limites réelles à ce que le comité va examiner, en particulier en ce qui concerne le deuxième point du mandat?

**La présidente:** Tout ce que je peux dire, c'est que, dans les *Journaux du Sénat*, le point 2 parle de faits nouveaux, au Canada, se rapportant aux questions traitées dans le rapport. On peut certainement se pencher sur quelques-unes des questions dont traitait le rapport, mais je pense qu'avant tout, notre comité doit étudier les progrès dans la mise en oeuvre des recommandations unanimes du rapport. À la rédaction de notre rapport final, ces recommandations seront au coeur de ce que nous écrirons. Je crois que c'est ce sur quoi nous devrions insister.

Cela dit, il y a des faits nouveaux, au Canada, qui s'ajouteront au document, mais nous ne passerons pas de jugement sur eux. Par exemple, si certaines causes juridiques viennent étoffer l'ensemble des connaissances, nous devrions y faire référence. Toutefois, je ne pense pas que nous devrions porter des jugements sur ces causes juridiques.

**Le sénateur Roche:** Je trouve vos commentaires fort utiles. J'aimerais cependant répéter que j'ai des réserves à ce sujet. Il serait peut-être possible de discuter à nouveau de la question en temps et lieu. Je crois que ce serait utile.

**La présidente:** Nous en discuterons certainement lorsque nous allons donner nos instructions à ceux qui vont rédiger le rapport final.

Nous allons maintenant commencer par le témoignage du Dr Lapointe.

[Français]

**M. Bernard Lapointe, président de l'Association canadienne des soins palliatifs et de l'Association québécoise de soins palliatifs:** Monsieur le président, la position de l'Association canadienne des soins palliatifs vous a été présentée il y a six ans par le Dr Ina Cummings, présidente de l'association à l'époque. Notre position sur les questions de l'euthanasie et du suicide assisté est demeurée inchangée depuis.

Ce matin, je vais concentrer mes commentaires, plus particulièrement, sur chacune des recommandations de votre rapport qui concernaient le développement des soins palliatifs.

Je tiens souligner, au nom de l'Association canadienne, le courage et le leadership dont vous avez fait preuve lors de l'examen de ces questions difficiles et douloureuses dans votre rapport de 1995. Je vous remercie de l'occasion qui nous est donnée de vous rencontrer ce matin et de vous faire rapport de l'évolution des soins palliatifs.

Comme vous l'avez noté dans votre rapport, plusieurs facteurs influencent la décision de demander le suicide assisté ou l'euthanasie: la douleur et les symptômes physiques non soulagés,



suffering, isolation or untenable living conditions, perception and reality of being a burden to spouse, family, society, or despair and lack of self-esteem which are the result of catastrophic illness.

[English]

As you know, the palliative care approach, as we describe it in the Canadian Palliative Care Association — you have the definition at page 4:

...is aimed at the relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved. It affirms life and regards dying as a normal process. It neither hastens nor postpones death. It provides relief from pain and other distressing symptoms. It integrates the psychological and spiritual aspects of patient care. It offers a support system to help patients live as actively as possible until death. It offers a support system to help the family cope during the patient's illness and their own bereavement.

The association is a national voice of hospice palliative care in this country. We represent over 18,000 volunteers and health care professionals across Canada, and we have 11 provincial member associations, of which l'Association québécoise de soins palliatifs is a member.

[Translation]

The Association québécoise de soins palliatifs has approximately 650 members spread out throughout the province.

[English]

The Canadian Palliative Care Association seeks to ensure excellence in the provision of hospice palliative care so that the burdens of suffering, loneliness and grief are reduced. It seeks to accomplish its mission through collaboration and representation with other national organizations.

Increased awareness, knowledge, and skills related to hospice palliative care is afforded the public through our 1-800 number, which is available to every Canadian in the country who wishes to know more about care, services and where to turn for help in their own community for health care providers and volunteers.

As well, we seek to achieve our objectives through the development of national standards of practice for hospice palliative care in Canada — and I will return to that topic later — the support of research in hospice palliative care and advocacy for improved hospice palliative care policy, resource allocation and support for caregivers.

I speak to you this morning with a sense of urgency. Despite some progress in improving access and qualities of care in some regions, we are seriously concerned about the future of end-of-life care for Canadians.

la dépression ou la souffrance psychologique, l'isolement ou encore des conditions de vie sous-humaines, la perception ou la réalité d'être un fardeau à la fois pour son conjoint, sa conjointe, sa famille ou la société, ou encore, le désespoir et une atteinte profonde de l'estime de soi qui accompagnent une maladie catastrophique.

[Traduction]

Comme vous le savez, l'approche des soins palliatifs, comme nous la décrivons, à l'Association canadienne des soins palliatifs — la définition se trouve en page 4:

[...] a pour objet de soulager la souffrance et d'améliorer la qualité de vie des personnes qui souffrent ou qui meurent d'une maladie en phase terminale, ou de leurs proches. Elle cherche à entretenir la vie, mais considère la mort comme un processus normal. Elle ne hâte ni ne retarde la mort. Elle cherche à soulager la douleur et tout autre symptôme pénible. Elle intègre les aspects psychologiques et spirituels des soins aux patients. Elle offre un système de soutien destiné à aider les patients à vivre le plus activement possible jusqu'à leur mort. Elle offre également un système de soutien pour aider les familles à mieux supporter la maladie du patient, de même que leur propre processus de deuil.

Notre association est un porte-parole national pour les soins palliatifs au pays. Nous représentons plus de 18 000 bénévoles et professionnels des soins de santé au Canada, et nous comptons parmi nos membres 11 associations provinciales, dont l'Association québécoise de soins palliatifs.

[Français]

L'Association québécoise de soins palliatifs compte environ 650 membres répartis dans les quatre coins de la province.

[Traduction]

L'Association canadienne des soins palliatifs cherche à assurer l'excellence dans la prestation des soins palliatifs, afin que la souffrance physique, la solitude et la souffrance morale soient réduites le plus possible. Elle cherche à s'acquitter de sa mission en collaborant avec divers organismes nationaux, et en se faisant représenter au sein de ces organisations.

Nous cherchons à sensibiliser le public aux soins palliatifs, à lui transmettre des connaissances à ce sujet et à lui faire connaître les compétences existantes dans ce domaine par le biais de notre ligne téléphonique sans frais, que peuvent consulter tous les Canadiens qui désirent en savoir plus long sur les soins et les services qu'ils peuvent obtenir au sein de leur propre communauté, auprès de bénévoles et de prestataires de soins de santé.

De même, nous cherchons à atteindre nos objectifs par le développement de normes nationales de pratique des soins palliatifs au Canada, et je reviendrai sur la question, par le soutien à la recherche dans le domaine et par des représentations sur la nécessité d'améliorer les politiques relatives aux soins palliatifs, l'attribution des ressources financières et le soutien aux soignants.

Ce matin, je suis venu vous dire que le temps presse. Malgré les quelques progrès réalisés dans l'accès et la qualité des soins dans certaines régions, nous sommes très inquiets à propos de l'avenir des soins palliatifs pour les Canadiens.

As you know, Canadian society is undergoing profound demographic changes. The population is ageing. As well, there is significant rise in the mortality rate predicted during the next 15 years.

These demographic changes highlight the acute need for palliative care services, and will fuel, undoubtedly, the debate over euthanasia and assisted suicide in our society. We all know that the Canadian population is ageing. However, the health care system and health policy are not planning adequately for this crisis. For example, on page 12, there is table that shows the growth of the number of Canadians over 85 years old, which will increase significantly over the coming decades — from 21,000 in 1921 to 140,000 in 1971. Statistics Canada estimated 400,000 people over 85 in 1998 and estimates that we will have over 1.6 million people over the age of 85 by the year 2041. As you all know, the most pressing needs for those over the age of 85 are social support and health care.

Statistics Canada underlined that, in 1996, 46 per cent of all the elderly in institutions were over 85 years old. We all know the prevalence of degenerative diseases, particularly Alzheimer's in this age group. The prevalence is high and rising.

The other point that accompanies the ageing population, and certainly an aspect that is less known, is the increase in the number of total deaths that will occur during the next decade or so. We do not have statistics from StatsCanada, but we have statistics from the Ministry of Health in Quebec that show that, from the year 1996, where we have an estimated number of 54,078 deaths, we will encounter, in 2015, 69,700 deaths. These numbers might look somewhat different. However, as you can see, the population will grow.

On the next page, we see the numbers per 100,000, which is where we see that there will be a significant increase, that is, 21 per cent of the number of deaths between 1996 and 2015 in Quebec. Every community in Canada will face a similar increase in the number of deaths. We know what that means in terms of the burden on these communities, the families, and so on.

The number of deaths will increase. The proportion of deaths in our community will increase. There is not only that to consider. We also know that the causes of these deaths will change. Since 1980, according to StatsCan, the number of deaths linked to cardiovascular disease has decreased significantly. There were 34 per cent fewer such deaths in 1996 than in 1980. However, the proportion of deaths caused by cancer and other degenerative diseases will continue to increase over the next decades. Therefore, more and more Canadians will need and demand competent, compassionate palliative care and end-of-life care.

Comme vous le savez, la société canadienne vit à l'heure actuelle de profonds changements démographiques. Notre population vieillit. Également, on prévoit une hausse importante du taux de mortalité pour les 15 prochaines années.

Ces changements démographiques montrent bien le besoin pressant qui existe pour les soins palliatifs et, sans aucun doute, ils seront à l'origine de nombreux débats sur l'euthanasie et sur l'aide au suicide dans notre société. Nous savons tous que la population canadienne vieillit. Malheureusement, le système de soins de santé et nos politiques en matière de santé ne se préparent pas de façon adéquate à cette crise potentielle. Par exemple, à la page 12, un tableau montre la croissance du nombre de Canadiens qui ont plus de 85 ans. Ce nombre va augmenter de façon importante au cours des prochaines décennies. Déjà, il est passé de 21 000 en 1921 à 140 000 en 1971. Statistique Canada a estimé à 400 000 le nombre de personnes de plus de 85 ans en 1998, et on estime qu'il y aura plus de 1,6 million de personnes ayant plus de 85 ans en l'an 2041. Comme vous le savez tous, les besoins les plus pressants pour les personnes de plus de 85 ans concernent le soutien social et les soins de santé.

Statistique Canada a souligné que, en 1996, 46 p. 100 de toutes les personnes âgées hospitalisées avaient plus de 85 ans. Nous savons tous que certaines maladies dégénératives, et notamment la maladie d'Alzheimer, touchent un nombre élevé et croissant de personnes de ce groupe d'âge.

L'autre facteur qui va de pair avec la population vieillissante, et qui est sans doute moins connu, est l'augmentation du nombre de décès totaux qui se produiront au cours de la prochaine décennie. Nous ne disposons pas de données publiées par Statistique Canada à ce sujet, mais il y a des statistiques publiées par le ministère de la Santé du Québec qui révèlent que, à partir de 1996, où il y a eu selon les estimations 54 078 décès, nous allons en arriver à 69 700 décès en l'an 2015. Ces chiffres peuvent paraître quelque peu différents. Toutefois, comme vous pouvez le constater, la population va augmenter.

À la page suivante, on voit les chiffres pour 100 000 habitants, ce qui nous permet d'en déduire qu'il y aura une hausse importante, c'est-à-dire 21 p. 100 du nombre de décès entre 1996 et 2015 au Québec. Toutes les collectivités du Canada connaîtront une augmentation équivalente du nombre de décès. Nous savons quel fardeau cela représente pour ces collectivités, les familles, etc.

Le nombre de décès va augmenter. La proportion de décès dans notre société va s'accroître. Ce n'est pas le seul facteur à prendre en ligne de compte. Nous savons également que la cause de ces décès va changer. Depuis 1980, selon Statistique Canada, le nombre de décès liés aux maladies cardiovasculaires a considérablement diminué. Il y en avait 34 p. 100 de moins en 1996 qu'en 1980. Toutefois, la proportion de décès dus au cancer et à d'autres maladies dégénératives va continuer d'augmenter au cours des prochaines décennies. Par conséquent, de plus en plus de Canadiens nécessiteront et exigeront des soins palliatifs et d'accompagnement en fin de vie assurés par des personnes compétentes et compatissantes.



We know from public opinion polls we have conducted and focus group consultations that we have held throughout the country that Canadians want to be sure that their loved ones are receiving the best possible end-of-life care. However, as I speak to you this morning, only a minority of Canadians has access to palliative care services. The majority of those dying do so unnecessarily in pain, suffering and discomfort. The quality of dying for most Canadians is determined by their disease, their social network, and their financial means. With health care being increasingly devolved to the family, the stability of the family is threatened by the financial and emotional burdens heaped upon them.

I will turn now to the recommendations contained in your 1995 report. The first recommendation is to make palliative care programs a top priority in the restructuring of the health care system. To my knowledge, only four Canadian provinces have palliative care designated as a core service with its own budget line. Since the publication of your report, the number of palliative care beds has been cut across Canada as a result of health care reform. The survival of many programs is in jeopardy because of the difficulty of recruiting physicians and other trained staff.

Because palliative care services are not adequately funded compared with other health care services, hospice and palliative care services rely disproportionately more on charitable donations for their survival, such as paying for nursing care, volunteer coordinators, psychologists, and so on. We have yet to see a national palliative care strategy with demonstrated leadership from the federal government.

There is no effective inter- or intra-departmental strategy planning taking place within Health Canada on issues of end-of-life care and hospice palliative care. Very little provision, if any, of palliative care exists on First Nations reserves or in federal penitentiaries.

Canadian Palliative Care Association operational funding from Health Canada through the National Voluntary Health Organizations Program has been terminated this year. Compared with the \$1 million received in operational funding by the Canadian AIDS Society each year, the Canadian Palliative Care Association was receiving \$30,000 annually.

The second recommendation of your report dealt with the development and implementation of national guidelines and standards being continued. In 1995, with Health Canada's support through the National AIDS Strategy, a preliminary consensus was achieved on a first round of these standards. In 1998, with funding from the Canadian Breast Cancer Initiative, a national consensus was achieved on 70 per cent of standards.

In 2000, the CPCA has received \$46,000 from Health Canada of an estimated \$450,000 in costs to complete and disseminate national standards. Progress toward completion is very slow.

Les sondages d'opinions que nous avons effectués et les consultations que nous tenues avec des groupes d'intérêts dans tout le pays nous apprennent que les Canadiens veulent être certains que leurs êtres chers reçoivent les meilleurs soins possible en fin de vie. Toutefois, à l'heure où nous nous parlons, seule une minorité de Canadiens ont accès à des soins palliatifs. La majorité des gens meurent inutilement dans la douleur, la souffrance et le malaise. La qualité de la mort de la plupart des Canadiens est fonction de la maladie dont ils souffrent, de leur réseau social et de leurs moyens financiers. Étant donné que les soins sont de plus en plus assurés par la famille, les fardeaux financiers et émotifs qu'elle doit assumer risquent de déstabiliser la famille.

Je voudrais maintenant parler des recommandations que renfermait votre rapport de 1995. La première visait à faire des programmes de soins palliatifs une priorité dans la restructuration du système de soins de santé. À ma connaissance, quatre provinces seulement ont désigné les soins palliatifs comme un service essentiel doté d'un budget propre. Depuis la publication de votre rapport, le nombre de lits pour les soins palliatifs a diminué dans tout notre pays à la suite de la réforme des services de santé. Le maintien de nombreux programmes est compromis à cause des problèmes qu'il y a à recruter des médecins et d'autres employés dûment qualifiés.

Étant donné que les services de soins palliatifs ne sont pas suffisamment financés en comparaison des autres services de santé, les services de soins palliatifs en hospice dépendent de façon disproportionnée des dons de charité pour être assurés, par exemple, pour rémunérer les infirmiers et infirmières, les coordonnateurs bénévoles, les psychologues, etc. Le gouvernement fédéral n'a pas encore fait preuve de leadership en proposant une stratégie nationale relative aux soins palliatifs.

Il n'existe aucune planification stratégique efficace inter ou intraministérielle envisagée à Santé Canada relativement aux questions touchant les soins palliatifs en hospice et l'accompagnement en fin de vie. Il n'existe pratiquement aucun service de soins palliatifs dans les réserves des Premières nations ou les pénitenciers fédéraux.

Cette année, Santé Canada a mis fin au financement opérationnel qu'il allouait à l'Association canadienne des soins palliatifs par le biais du programme national des organisations bénévoles de santé. Comparativement à la Société canadienne du SIDA qui reçoit un million de dollars par an de financement opérationnel, l'Association canadienne des soins palliatifs recevait 30 000 \$ par an.

La deuxième recommandation de votre rapport portait sur la poursuite de l'élaboration et de la mise en oeuvre de lignes directrices et de normes nationales. En 1995, avec l'appui de Santé Canada par le biais de la Stratégie nationale sur le sida, on a atteint un consensus préliminaire à l'égard d'une première série de normes. En 1998, grâce au financement d'initiatives canadiennes de lutte contre le cancer du sein, on s'est entendu au niveau national sur 70 p. 100 de normes.

En l'an 2000, l'Association a reçu 46 000 \$ de Santé Canada sur un montant estimé de 450 000 \$ de frais liés à la mise au point et à la diffusion de normes nationales. Cette initiative

Canada needs national standards to ensure that all Canadians have access to high-quality hospice palliative care services. Without national standards, the potential exists for substandard end-of-life services and undue suffering. I refer here to people who proclaim that they deliver palliative care services in the home. We have seen hospices in which patients have had to be carried on the back of a volunteer to the second floor. We have seen substandard nutritional status of those patients and so on.

Another of your recommendations dealt with the training of health care professionals in all aspects of palliative care being increased. I have to report to you that the creation of the new certificate in palliative medicine developed jointly by the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada is a significant step in the right direction. However, as we speak this morning, only 7 of the 16 Canadian medical colleges have applied to offer this program.

Despite all we know about the growing need for end-of-life care and the explosion of clinical knowledge in the field, only a minority of medical, nursing, social work, psychology and other health care programs offer palliative care training. There is no accreditation process in Canada to ensure professional competence in palliative care for those who are practising in their field.

Another of your recommendations was that there be an integrated approach to the delivery of palliative care, whether in the home, in hospices or in institutions with the support of volunteers. You state that that must be coordinated to maximize effectiveness and that the provision of respite services is an essential component. With the exception of certain initiatives in Calgary, Edmonton, Ottawa, and certain parts of Montreal, this remains wishful thinking. Health care budget cuts have prevented support for the development of partnerships and collaboration models. For most Canadians, the choice of where they will be cared for does not exist. Whether they live in inner cities or in rural Canada, a large proportion of the elderly cannot count on family support when facing life-threatening illness. Respite care is rare and, as a result, caregiver burnout leads to rehospitalization.

Your last recommendation was that research into palliative care, especially pain control and symptom relief, be expanded and improved. We share with you the affirmation that the most promising approach to improving the quality of palliative end-of-life care for Canadians is the generation of new knowledge through research. The Canadian Palliative Care Association has invested a great deal of effort in promoting the need for palliative care research in developing — for instance, a Canadian agenda for research in palliative care, conducting meetings throughout the

progresse à pas de tortue. Le Canada doit se doter de normes nationales pour s'assurer que tous les Canadiens ont accès à des services de soins palliatifs en hospice de qualité. Faute de normes nationales, il risque d'y avoir des services d'accompagnement des mourants de qualité inférieure et des souffrances injustifiées. Je parle ici des gens qui prétendent assurer des soins palliatifs à domicile. Nous avons vu des hospices où les patients ont dû être portés à dos d'homme par des bénévoles, au deuxième étage. Il y a aussi parmi ces patients des gens dont l'état nutritionnel est inacceptable, et j'en passe.

Une autre de vos recommandations prévoyait une expansion des cours de formation offerts aux professionnels de la santé dans tous les domaines des soins palliatifs. Je dois vous dire que le nouveau certificat de médecine palliative créé conjointement par le Collège des médecins de famille du Canada et le Collège royal des médecins et chirurgiens du Canada représente un énorme pas dans la bonne direction. Toutefois, à l'heure où nous nous parlons, seulement 7 des 16 collèges médicaux canadiens ont fait une demande pour offrir ce programme.

Malgré tout ce que nous savons au sujet de l'importance croissante des soins d'accompagnement en fin de vie et de l'explosion des connaissances cliniques dans ce domaine, seule une poignée de programmes de soins médicaux, infirmiers et de travail social, de psychologie et d'autres soins de santé comprennent des cours en soins palliatifs. Il n'y a pas de processus d'accréditation au Canada qui garantisse la compétence professionnelle dans les soins palliatifs pour ceux qui exercent dans leur domaine.

Votre comité avait également recommandé d'adopter une stratégie intégrée relativement à la prestation des soins palliatifs, que ce soit à domicile, dans les hospices ou dans les établissements de santé, avec l'aide des bénévoles. Vous dites qu'il faut coordonner tous les services pour garantir une efficacité maximum et que les soins de relève constituent un élément essentiel. À l'exception de certaines initiatives mises sur pied à Calgary, Edmonton, Ottawa et dans certains quartiers de Montréal, ce projet est encore illusoire. Les réductions touchant les budgets des soins de santé ont entravé l'élaboration de partenariats et de modèles de collaboration. La plupart des Canadiens n'ont pas le choix de l'endroit où ils seront soignés. Qu'ils habitent au centre-ville ou dans les régions rurales du pays, une bonne partie des personnes âgées ne peuvent pas compter sur l'appui de leur famille lorsqu'elles sont atteintes d'une maladie grave. Les soins de relève sont rares et, de ce fait, l'épuisement des personnes soignantes oblige les malades à être réhospitalisés.

Votre dernière recommandation prévoyait la poursuite et l'amélioration des recherches sur les soins palliatifs, et notamment le contrôle de la douleur et l'allègement des symptômes. Nous convenons avec vous que la meilleure façon d'améliorer la qualité des soins palliatifs offerts aux Canadiens en fin de vie consiste à accroître nos connaissances grâce à la recherche. L'Association canadienne des soins palliatifs n'a ménagé aucun effort pour insister sur l'utilité des recherches sur les soins palliatifs — par exemple, un programme canadien de recherche sur les soins



country, and consultations with members of the public, caregivers and the teams of researchers in 1999.

We have as well held protracted and, unfortunately, unsuccessful negotiations with Health Canada to develop a Canadian palliative care initiative focusing on training and research.

An analysis conducted by an independent consultant firm of funding provided by three key research funding agencies over the past five years confirmed the relative lack of research support being received in the field of palliative care.

In fact, the two major agencies that provide ongoing programmatic research funding to Canadian investigators, the Medical Research Council and the National Cancer Institute of Canada, have supported just a few operating grants in palliative care research, amounting to a tiny fraction of their overall funding for health research in this country.

The lack of sustained funding from the two national funding bodies, MRC and NCIC, represents a major impediment to the generation of new knowledge that could improve care for dying patients and their families in Canada.

Since the publication of your report, Canada has lost a significant number of key researchers. If we look at the ten key researchers we had then, in 1995, we have lost four to other countries over the last three years. The total absence of end-of-life research and palliative care research from the new Canadian Institutes of Health Research structure, despite considerable advocacy by CPCA and its members, speaks of a bleak future.

The current lack of capacity in the form of independent investigators in the field of end-of-life and palliative care research is a significant barrier to progress. Only an immediate and concerted research strategy aimed at capacity building will allow the emerging field of palliative care research to survive over the next decade in this country.

In conclusion, the hospice and palliative care community of this country is very appreciative of the clear recognition in the 1995 Senate report of the value of the palliative care approach for all Canadians facing life-threatening illness and their families. In this presentation, we have highlighted the relative lack of action on your 1995 recommendations. We urge you to show strong leadership so that all Canadians will benefit from competent and compassionate end-of-life care and that no Canadian will consider euthanasia and assisted suicide as their only way of exercising control over a life filled with pain, emotional suffering, social isolation, and the feeling of being a burden to their family and society.

palliatifs, l'organisation de réunions dans tout le pays ainsi que des consultations avec le grand public, les fournisseurs de soins et l'équipe de chercheurs en 1999.

Nous avons également entrepris des négociations interminables et malheureusement infructueuses avec Santé Canada en vue d'élaborer une initiative canadienne de soins palliatifs axée sur la formation et la recherche.

Il ressort d'une analyse effectuée par une entreprise de conseil indépendante sur le financement accordé au cours des cinq dernières années par trois importants organismes de financement de la recherche que l'on ne soutient pas suffisamment la recherche dans le domaine des soins palliatifs, toutes proportions gardées.

En fait, les deux principaux organismes qui offrent un financement permanent aux chercheurs canadiens, le Conseil de recherches médicales et l'Institut national du cancer du Canada, n'ont financé que quelques subventions de fonctionnement pour la recherche sur les soins palliatifs, ce qui représente une fraction minime du financement global alloué à la recherche sur la santé dans notre pays.

L'absence de financement soutenu de la part des deux principaux organismes nationaux de financement de la recherche, soit le CRM et le INCC, constitue un obstacle sérieux à la création de nouvelles connaissances susceptibles d'améliorer les soins offerts aux mourants et à leurs familles au Canada.

Depuis la publication de votre rapport, le Canada a perdu un nombre important de ses principaux chercheurs. Sur les 10 principaux chercheurs que nous avions à l'époque, en 1995, quatre ont quitté le Canada pour d'autres pays au cours des trois dernières années. Les perspectives d'avenir semblent bien sombres si l'on tient compte du fait que la nouvelle structure des instituts canadiens de recherche en santé ne prévoit absolument aucune recherche sur les soins palliatifs et les mesures d'accompagnement des mourants, malgré l'énergie que notre association et ses membres ont consacrée à la défense de cette cause.

La pénurie actuelle de chercheurs indépendants dans le domaine des soins palliatifs et de l'accompagnement des mourants représente un obstacle important au progrès. Seule une stratégie de recherche immédiate et concertée visant à accroître la capacité de recherche permettra au nouveau domaine que représente la recherche des soins palliatifs de se maintenir au cours de la prochaine décennie dans notre pays.

Pour conclure, les responsables des soins en hospice et des soins palliatifs de notre pays sont très reconnaissants au Sénat d'avoir reconnu clairement dans son rapport de 1995 l'importance que revêtent les soins palliatifs pour tous les Canadiens atteints de maladie mortelle et leurs familles. Dans notre témoignage, nous avons fait ressortir le fait que vos recommandations de 1995 n'ont guère eu de suite. Nous vous demandons instamment de faire preuve de leadership pour que tous les Canadiens reçoivent en fin de vie des soins assurés par des personnes compétentes et compatissantes et qu'aucun Canadien ne considère l'euthanasie et l'aide au suicide comme la seule façon pour lui d'exercer un contrôle sur une vie faite de douleur, de souffrance affective,

**The Chairman:** I was not surprised by your remarks, although they were even stronger than I thought they might be. I appreciate your forthrightness.

I now call on Dr. MacLachlan.

**Dr. Richard MacLachlan, Head, Faculty of Medicine, Dalhousie University, College of Family Physicians of Canada:** Madam chair, I greatly appreciate the opportunity to appear before the Senate for the second time in six years for this important continuing discussion. At both appearances, I have been representing the College of Family Physicians of Canada. I have included some information about the college in the brief, which I hope was circulated to you this morning. It is available in both official languages. I will not repeat that information here, but suffice it to say our college is a voluntary organization that represents over 15,000 family doctors in Canada. We as a group provide the primary medical care to the majority of Canadians.

I would like to highlight the activities of the college's committee on ethics in the intervening five years since we appeared here in November 1994. Following the release of your report "Of Life and Death" in June 1995, we continued the discussion of the issues we raised in our brief to you the previous November and your report and recommendations. We felt it was important to encourage national discussion of these issues and, following an extensive consultation, published a discussion paper in the *Canadian Family Physician*, our journal of the college, which is circulated to an excess of 30,000 Canadian general practitioners, family doctors. The article was published in February 1997, and we titled it "Lobbying the lawmakers: the College and Assisted Death." You should have a copy of that article in the package that was delivered to you this morning. In that article, we tried to outline the background behind our presentation to you in 1994 and our feeling that we needed urgent public and professional debate on this topic concurrent with governmental action. We welcomed advice from readership on this topic.

During the subsequent two years, calendar years 1997 and 1998, we continued active discussion of the issue, including analysis of the rather overwhelming input we received from the readers of our 1997 article. Based on that input and our thinking at the time, we drafted a statement on euthanasia and assisted suicide, which we circulated to two other committees of our college, the committee on health care of the elderly and the committee on palliative care, as well as other key individuals in the health care profession nationally. We put those three committees together in November 1998 for a real thrashing out of the statement and made major changes to it. The following month, December 1998, we took our statement on euthanasia and assisted suicide to the board of directors of the College of Family Physicians of Canada and it was adopted unanimously by them.

d'isolement social, outre le sentiment d'être un fardeau pour sa famille et la société.

**La présidente:** Vos observations ne m'ont pas surprise, même si elles ont été encore plus catégoriques que ce à quoi je m'attendais. Je vous sais gré de votre franchise.

J'invite maintenant le Dr MacLachlan à se présenter.

**M. Richard MacLachlan, directeur, faculté de médecine, Université Dalhousie, Collège des médecins de famille du Canada:** Madame la présidente, j'apprécie beaucoup l'occasion qui m'est offerte, pour la deuxième fois en six ans, de comparaître devant le Sénat pour participer à cette importante discussion. En ces deux occasions, j'ai représenté le Collège des médecins de famille du Canada. Dans le mémoire qui vous a été distribué ce matin, du moins je l'espère, se trouvent certains renseignements au sujet du collège. Ce mémoire est disponible dans les deux langues officielles. Je ne répéterai pas ce qui s'y trouve, mais je dirai simplement que notre collège est un organisme bénévole qui représente plus de 15 000 médecins de famille au Canada. Notre groupe offre des soins médicaux primaires à la majorité des Canadiens.

J'aimerais vous présenter les activités du comité d'éthique du collège au cours des cinq années qui ont suivi notre comparution en novembre 1994. À la suite de la publication de votre rapport intitulé «De la vie et de la mort» en juin 1995, nous avons poursuivi nos discussions sur les questions soulevées dans le mémoire que nous vous avons présenté au mois de novembre précédent et sur votre rapport et vos recommandations. Il nous apparaissait important d'encourager le débat national sur ces questions et, à l'issue de notre consultation élargie, nous avons publié un document de travail dans *Le médecin de famille canadien*, la revue du collège qui est distribuée à plus de 30 000 généralistes et médecins de famille canadiens. L'article publié en février 1997 s'intitulait «Lobbying the lawmakers: the College and Assisted Death». Vous trouverez le texte de cet article dans la trousse d'information qui vous a été remise ce matin. Dans cet article, nous avons essayé de situer le contexte de notre témoignage devant votre comité en 1994 ainsi que notre sentiment du besoin urgent d'un débat public et professionnel sur ce sujet, parallèlement à une initiative gouvernementale. Nous incitions également nos lecteurs à nous donner leur avis à ce sujet.

Au cours des deux années qui ont suivi, soit en 1997 et 1998, nous avons poursuivi activement nos discussions sur le sujet, y compris l'analyse des très nombreuses réponses de nos lecteurs après la publication de l'article de 1997. En fonction de ces commentaires et de notre position de l'époque, nous avons rédigé un énoncé de principe sur l'euthanasie et l'aide médicale au suicide qui a été présenté à deux autres comités du collège, notamment le comité des soins aux personnes âgées et le comité des soins palliatifs, ainsi qu'à certains autres intervenants importants du domaine des soins de santé dans tout le pays. Nous avons tenu une réunion regroupant les trois comités en novembre 1998 en vue de remanier notre énoncé de principe et nous y avons apporté des changements en profondeur. Le mois suivant, en décembre 1998, nous avons présenté notre énoncé de principe sur l'euthanasie et l'aide médicale au suicide au conseil



The college's committee on ethics subsequently circulated the statement on euthanasia and assisted suicide to all 16 medical schools in Canada, the licensing authorities, and other key individuals. Nevertheless, we felt the need to ensure wider dissemination of the statement, and we have worked to develop an explanatory article, which was actually — perhaps this is more good fortune than good timing — published last Friday and circulated to 32,000 Canadian family physicians today. It is the lead editorial in the February issue of the *Canadian Family Physician*. You should have a copy of that also in your brief. I think it will trigger significant discussion of the issues.

I wish to point out that the pre-print copy you have has one typographical error. It says that it was adopted in December 1999 when in fact it was December 1998, as I mentioned. That has been corrected for the journal, but you got a slightly premature copy.

What we have tried to do in this editorial, and indeed in our statement, is to demarcate what is good, ethically acceptable clinical practice and what activities at the present time are illegal in Canada. We have tried where possible to restate what we felt were clear statements of facts in your document "Of Life and Death." For example, the statement that "a decision to withhold or withdraw certain treatments might result in an earlier death of a patient, but this consequence is ethically acceptable and legally permissible if carefully and thoughtfully made," I believe is entirely congruent with your report.

We focused on the importance of ascertaining patients' wishes, including their possible wish to forgo life-sustaining treatment, ideally well in advance of any crisis. We noted the need to involve other family members in decision making, particularly when the patient was no longer capable of expressing his or her wishes. We focused on the intent of care, noting as you did in "Of Life and Death," that "providing treatment aimed at alleviating suffering that may shorten life is legal."

We tried to be explicit that "all care aimed at alleviating symptoms due to advanced, terminal disease is ethically acceptable and legally permissible if administered to relieve the patient's suffering, if it is commensurate with that suffering, and if it is not a deliberate infliction of death."

We noted that concerns that treatments aimed at alleviating suffering might occasionally hasten a patient's death were overstated, particularly as it relates to increasing doses of opioids or narcotics. We noted the reality is that the suffering of many dying patients is caused by, or related to, being undertreated.

d'administration du Collège des médecins de famille du Canada qui l'a adopté à l'unanimité.

Le comité d'éthique du collège a ensuite distribué l'énoncé de principe sur l'euthanasie et l'aide médicale au suicide aux 16 facultés de médecine du Canada, aux organismes d'accréditation et à d'autres intervenants importants. Néanmoins, nous avons senti le besoin de diffuser plus largement l'énoncé et avons décidé de rédiger un article explicatif, lequel a été — peut-être est-ce plus un heureux hasard qu'une circonstance opportune — publié vendredi dernier et distribué aujourd'hui à 32 000 médecins de famille canadiens. Cet article est publié en éditorial du numéro de février de la revue *Le médecin de famille canadien*. Vous en avez également une copie dans votre mémoire. Je pense que cela suscitera une discussion importante sur ces questions.

Je tiens à signaler que la copie que vous avez en main referme une coquille. Il y est dit que cet énoncé a été adopté en décembre 1999 alors qu'il s'agit de décembre 1998, comme je vous l'ai dit. L'erreur a été corrigée pour la revue, mais vous avez reçu une copie préliminaire.

Dans cet éditorial, et dans notre énoncé, nous avons tenté de délimiter ce que nous considérons une bonne pratique clinique qui soit acceptable du point de vue éthique et les activités qui sont actuellement illégales au Canada. Dans la mesure du possible, nous avons essayé de réitérer certains énoncés factuels clairs de votre rapport intitulé «De la vie et de la mort». Par exemple, la déclaration selon laquelle «la décision de cesser ou de refuser certains traitements pourrait précipiter le décès d'un patient, mais cette conséquence est acceptable sur le plan éthique et permissible légalement si elle est prise après mûre réflexion», est à mon avis tout à fait conforme à l'esprit de votre rapport.

Nous nous sommes concentrés sur l'importance de déterminer ce que souhaitent les patients, et notamment leur désir éventuel de renoncer à tout traitement susceptible de prolonger la vie, idéalement bien avant que la crise ne surgisse. Nous avons signalé qu'il faut faire participer les autres membres de la famille aux décisions qui sont prises, surtout quand le patient n'est plus en mesure d'exprimer ses souhaits. Nous nous sommes concentrés sur l'intention des soins, soulignant, comme vous le faisiez dans votre document «De la vie et de la mort», que: «Il est légal d'offrir un traitement dans le but de soulager la souffrance même s'il risque de précipiter le décès.»

Nous avons essayé d'être explicites à l'effet que «tous les soins visant à soulager les symptômes imputables à une maladie avancée et terminale sont acceptables sur le plan éthique et permisibles légalement s'ils sont administrés pour soulager la souffrance du patient, s'ils sont proportionnés au degré de souffrance et s'ils ne sont pas un geste délibéré pour provoquer la mort.»

Nous avons noté une exagération des préoccupations entourant le fait que les traitements visant à soulager la souffrance puissent à l'occasion accélérer la mort du patient, surtout en ce qui a trait aux doses excessives d'opiacés ou de narcotiques. Nous avons souligné que, en réalité, la souffrance de nombreux patients

We urged readers, whether professionals or lay, to continue discussions on these important topics, and we welcomed feedback to the statement. The feedback since it was released 14 months ago has been overwhelmingly positive.

As I look back at the discussions in 1994 and 1995, I would contend that the Special Senate Committee on Euthanasia and Assisted Suicide seemed to be challenging organized medicine, our professional associations and medical schools to take leadership on these issues. I would contend that “we have gone as far as we can go” — to quote Rogers and Hammerstein — without legislative reform and other governmental action, as recommended in your 1995 report.

There is much unfinished business relating to the recommendations included in “Of Life and Death.” You have requested input and advice. We were certainly encouraged that the recommendations that we made to the Senate in 1994 were largely incorporated in your 1995 report. Unfortunately, my feelings are similar to those of Dr. Lapointe, that there has been little perceptible activity in the intervening five years. Your chair, Senator Carstairs, in her motion establishing the subcommittee, indicated that your mandate should be to examine the progress on the implementation of the unanimous recommendations in your report, so what I will do is try to respond section by section to your 1995 report.

Your first chapter with recommendations was chapter 3 on palliative care. I would agree with Dr. Lapointe that there has been little discernible government action on the five recommendations. I would acknowledge that there has been some discussion of increased attention to home care. As Dr. Lapointe noted, the Royal College of Physicians and Surgeons and my college, the College of Family Physicians of Canada, have agreed upon a common one year of extra training acceptable to both colleges following certification by either college. Whether you come out of a royal college program in neurology or cancer care or respiration or come out of my program in family medicine, you will do one common year and be certified with special competence in palliative care. Our colleges have come together and created the framework for programs to submit proposals. Those are underway right now with the possibility that these programs will commence this coming summer. However, to put on residency programs requires governmental support. It is only the minority of medical schools that have been able to get that support to launch these residency programs.

With respect to the development and implementation of national guidelines and standards for palliative care, as you recommended in 1995, our palliative care committee of the college is currently developing clinical guidelines for care at the end of life. We were not aware of any significant expansion and

mourants est causée par un traitement insuffisant, ou est associée à celui-ci.

Nous avons incité nos lecteurs, qu'ils soient professionnels ou profanes, à poursuivre leurs discussions sur ces questions importantes et avons demandé leurs commentaires au sujet de notre énoncé. Depuis la publication de cet article il y a 14 mois, la réaction a été extrêmement positive.

Lorsque je repense aux discussions qui ont eu lieu en 1994 et 1995, j'affirme que le comité sénatorial spécial sur l'euthanasie et l'aide au suicide mettait apparemment au défi la médecine conventionnelle, nos associations professionnelles et les facultés de médecine de faire preuve de leadership dans ce domaine. Je soutiens que nous avons fait notre maximum — pour citer Rogers et Hammerstein — sans procéder à une réforme législative ni sans la moindre initiative gouvernementale, comme le recommandait votre rapport de 1995.

Il reste encore beaucoup à faire pour donner suite aux recommandations que renfermait le rapport «De la vie et de la mort». Vous avez demandé des conseils et des commentaires. Il nous a paru très encourageant de voir que les recommandations que nous avions faites au Sénat en 1994 étaient en grande partie incorporées dans votre rapport de 1995. Malheureusement, et là mon sentiment rejoint celui du Dr Lapointe, il y a eu peu d'activités perceptibles au cours des cinq dernières années. La présidente de votre comité, le sénateur Carstairs, dans sa motion visant à établir le sous-comité, a indiqué que celui-ci avait pour mandat d'examiner les progrès réalisés pour mettre en oeuvre les recommandations unanimes de votre rapport, et c'est pourquoi je vais essayer de répondre point par point à votre rapport de 1995.

Le premier chapitre comportant des recommandations était le chapitre 3, sur les soins palliatifs. Je conviens avec le Dr Lapointe qu'il y a eu peu d'initiatives perceptibles de la part du gouvernement pour donner suite aux cinq recommandations. Je reconnais que l'on a parlé d'accorder une attention accrue aux soins à domicile. Comme l'a signalé le Dr Lapointe, le Collège royal des médecins et des chirurgiens et mon collège, le Collège des médecins de famille du Canada, se sont entendus pour offrir une année commune supplémentaire de formation en soins palliatifs qui sera acceptable pour les deux collèges, suivent l'accréditation par l'un ou l'autre. Que l'on ait terminé un programme du collège royal en neurologie ou en oncologie ou en soins respiratoires, ou que l'on ait terminé mon programme en médecine familiale, les futurs médecins feront une année commune de spécialisation en soins palliatifs. Nos collègues se sont entendus pour établir le cadre des programmes afin de soumettre des propositions. Celles-ci sont en cours à l'heure actuelle et il est possible que les programmes débutent dès l'été prochain. Toutefois, il faut l'appui du gouvernement pour mettre en place des programmes de formation. Une poignée seulement des facultés de médecine ont réussi à obtenir cette aide pour entreprendre ces programmes de formation des médecins.

Quant à l'élaboration et à la mise en oeuvre de lignes directrices et de normes nationales pour les soins palliatifs, comme vous l'avez recommandé en 1995, le Comité des soins palliatifs du collège élabore actuellement un guide de pratique clinique pour les soins aux patients mourants. Nous n'avons pas



improvement of what you recommended — that is, research into palliative care, especially pain control and symptom relief — beyond the Health Canada support for the Canadian Palliative Care Association to establish a working group to look at what the research agenda should be, as Dr. Lapointe described earlier.

We need to recall that this is five years later, and we are looking at support to develop an agenda. I think we have lost a crucial five-year period for this research activity. As I said to the Senate in 1994, and you quote in your report, “only with a comprehensive palliative care program available throughout the country should there be consideration of assisted suicide or euthanasia”. My feelings have not changed.

Chapter 4 concerns pain control and sedation practices. We are aware of little, if any, progress on the recommendations in this section. Indeed, the case of *Regina v. Dr. Nancy Morrison* in Nova Scotia — and, this was based at my hospital, where all criminal charges are now dismissed — has put a chill on appropriate analgesic management of dying patients. Your report stated, on page 31, that “the committee recognizes that providing treatment aimed at alleviating suffering that may shorten life is legal.” Your first recommendation in chapter 4 was that “the Criminal Code be amended to clarify the practice of providing treatment for the purpose of alleviating suffering that may shorten life.”

The failure to indicate what specific amendment was needed to support your first statement and the absence of legislative initiative may have, perhaps inadvertently, only added to the confusion and, potentially, the under treatment of our patients.

Chapter 5 concerns withholding and withdrawal of life-sustaining treatment. We are aware of little, if any, progress on the five recommendations in this section. As I mentioned earlier, our college has amended our professional guidelines to be consistent with your report, but we have gone as far as we can go. We cannot proceed with further amendment of our professional guidelines without the legislative changes and other government actions contained in your 1995 report.

Chapter 7 relates to assisted suicide. We are not aware of any activity on the two recommendations for change in this section.

Chapter 8 covers euthanasia. This is often challenged with the current interpretation of euthanasia, but we must remind ourselves that the Greek interpretation means “good death”. We would all advocate good death, but in the context of your report “euthanasia” has a different interpretation. We are not aware of

constaté de changement ni de progrès important faisant suite à vos recommandations — c’est-à-dire la recherche en soins palliatifs, particulièrement sur le contrôle de la douleur et le soulagement des symptômes —, à l’exception de l’aide offerte par Santé Canada à l’Association canadienne des soins palliatifs pour qu’elle constitue un groupe de travail dont le mandat serait de se pencher sur le contenu du programme de recherche, comme l’a signalé plus tôt le Dr Lapointe.

Il faut se rappeler que cinq ans se sont écoulés et que l’on attend encore une aide financière pour élaborer un programme. À mon avis, nous avons perdu une période cruciale de cinq ans pour amorcer ces recherches. Comme je l’ai dit devant le Sénat en 1994, et comme vous le rappelez dans votre rapport, on ne pourra envisager l’euthanasie ou l’aide médicale au suicide que lorsqu’il existera dans tout le pays un programme global de soins palliatifs. Mes sentiments n’ont pas changé sur ce point.

Le chapitre 4 traite du contrôle de la douleur et des pratiques de sédation. À notre connaissance, peu de progrès ont été faits pour donner suite aux recommandations contenues dans ce chapitre. En fait, la cause *Regina c. Dr. Nancy Morrison* en Nouvelle-Écosse — et cela se passait dans mon hôpital, où toutes les poursuites criminelles ont été depuis abandonnées — nous laisse songeurs sur le traitement analgésique approprié à administrer aux patients mourants. Vous disiez à la page 33 de votre rapport que «le comité reconnaît qu’administrer un traitement destiné à soulager la souffrance au risque d’abrégé la vie est légal.» Votre première recommandation au chapitre 4 prévoyait «que le Code criminel soit modifié afin de clarifier la situation concernant l’administration d’un traitement destiné à soulager la souffrance au risque d’abrégé la vie.»

Le fait de n’avoir pas précisé quelle modification il fallait apporter pour étayer votre première recommandation et l’absence d’initiative d’ordre législatif ont peut-être accidentellement ajouté de la confusion à toute cette question, et risqué d’entraîner le sous-traitement de nos patients.

Le chapitre 5 traite de l’abstention et de l’interruption de traitement de survie. À notre connaissance, il n’y a guère eu de progrès entourant les cinq recommandations de ce chapitre. Comme je l’ai dit plus tôt, notre collège a modifié ses lignes directrices professionnelles pour qu’elles soient conformes à votre rapport, mais nous ne pouvons pas faire plus. Nous ne pouvons pas continuer à modifier nos lignes directrices professionnelles si le gouvernement ne modifie pas la législation en vigueur ou ne prend pas d’autres mesures comme le recommande votre rapport de 1995.

Le chapitre 7 porte sur l’aide au suicide. Nous ne sommes témoins d’aucune activité donnant suite aux deux recommandations de changement que renferme ce chapitre.

Le chapitre 8 porte sur l’euthanasie. Cette question est souvent remise en cause par l’interprétation actuelle du terme euthanasie, mais il ne faut pas oublier que, selon l’étymologie grecque, cela signifie «bonne mort». Nous recommandons tous une bonne mort, mais dans le contexte de votre rapport, on interprète différemment

any progression on the two unanimous recommendations in this section requiring specific action by government.

In summary, I would echo Dr. Lapointe's comments that we are grateful the Senate has chosen to reactivate discussion on this important topic after five years of virtual inactivity. Public discussion continues, including a lot of attention this last week on the front pages of national papers. The college has attempted to foster public and professional discussion on these crucial and complex issues. Our statement on euthanasia and assisted suicide has been welcomed by many as an important step forward. We ask you to review it carefully as you proceed to build on the work done by the Senate in 1994-95.

The lack of parliamentary action on your 1995 report is clearly causing unjustifiable, continuing confusion, pain and suffering for patients, their families and care givers.

**The Chairman:** A number of senators have already indicated that they want to be on the questioning list.

[Translation]

**Senator Pépin:** Dr. Lapointe, there is much talk about reduced services due to hospital budget reductions. It seems that health care reform is focussing more on home care. If we are to make new accommodations regarding health care services, don't you think that home care will receive more attention? Should we focus specifically on home care?

It would be cheaper for hospitals but more expensive for patients. The more seriously ill patients will have to be hospitalized, of course, but there is an increasing trend towards sending people home. So should we not pay more attention to home care services?

**Dr. Lapointe:** For most of us, home is the best place to be. It is where we live with our family, it is the place where our relations take place and it lies within our community. That is where life unfolds and, of course, everything revolves around home.

However, we have to destroy the myth that every terminally-ill patient wants to be at home. Last year, polls showed that most Canadians would rather be looked after at home if they were terminally ill.

However, when we broke down the poll by age group, we realized that the desire to stay home falls off as people reach age 65 and beyond. Fewer people aged 75 and over want to stay home, whereas after the age of 85, the opposite happens: people would rather not be looked after at home anymore for several reasons.

l'euthanasie. À notre connaissance, aucun progrès n'a été fait pour donner suite aux deux recommandations unanimes de ce chapitre qui incitaient le gouvernement à prendre des mesures précises.

En résumé, je réitère les remarques du Dr Lapointe, selon lesquelles nous sommes reconnaissants au Sénat d'avoir décidé de relancer le débat sur cet important sujet après cinq ans de quasi-inactivité. Le dialogue public se poursuit, et cette question a fait l'objet d'un grand nombre de manchettes dans les journaux nationaux la semaine passée. Le collège s'est efforcé de favoriser un débat public et professionnel sur ces questions cruciales et complexes. Notre énoncé sur l'euthanasie et l'aide médicale au suicide a été bien accueilli par de nombreuses personnes qui le considèrent comme un important pas en avant. Nous vous demandons de bien vouloir l'examiner attentivement lors de vos délibérations visant à donner suite aux travaux amorcés par le Sénat en 1994-1995.

L'absence d'initiative parlementaire à la suite de votre rapport de 1995 entretient manifestement une confusion injustifiable et cause inutilement des souffrances aux patients, à leurs familles et aux personnes qui les soignent.

**La présidente:** Un certain nombre de sénateurs ont déjà indiqué qu'ils ont des questions à vous poser.

[Français]

**Le sénateur Pépin:** Docteur Lapointe, on parle de tous les services qui ont été réduits à cause des réductions dans les budgets des hôpitaux. Le virage des différents services de santé semble s'orienter vers les services à domicile. Si de nouvelles recommandations sont faites relativement aux services qui seront offerts, ne croyez-vous pas que les services à domicile occuperont une plus grande place? Devrait-on porter une attention particulière à la question des services à domicile?

Il en coûtera moins cher aux hôpitaux et plus cher aux patients. Les gens les plus gravement malades doivent bien sûr aller dans les hôpitaux, mais de plus en plus, il y a une tendance à retourner les gens à domicile. Ne devrait-on pas porter une attention particulière aux services à offrir à ces gens?

**M. Lapointe:** Pour la plupart d'entre nous, le domicile représente le lieu où la qualité de vie peut être optimisée. C'est le lieu où on vit avec notre famille, nos relations et notre communauté. La vie s'y déroule et le pivot en est, bien sûr, le domicile.

Cependant, il faut briser le mythe du désir d'être à domicile de toutes les personnes confrontées à une maladie terminale. En réalité, des sondages effectués l'an dernier démontrent que l'ensemble des Canadiens veulent être soignés à domicile s'ils étaient atteints d'une maladie terminale.

Toutefois, lorsqu'on examine la question par tranches d'âge, on s'aperçoit que la réponse est de moins en moins forte au fur et à mesure qu'on dépasse 65 ans. À 75 ans et plus, la réponse est moins forte et après 85 ans, c'est le contraire qui se produit: on ne souhaite plus être soigné à domicile pour plusieurs raisons.



One of these reasons is the absence of a natural caregiver, such as a member of the family who is able to look after the loved one, such as the spouse or a child. Just think of the elderly who live in remote villages in Gaspésie whose children have moved to the city, or people who are isolated downtown and who cannot see members of their family.

Also, when you have a terminally-ill person at home, they may die there. Home care is a good idea when the conditions are right. But there have to be alternatives.

In Canada, some specialized institutions within the communities create a home for the seriously ill and hospital services are offered for those who request it. We know that most of the costs of home care are paid by the family.

The presence of health care personnel is limited by the budgets that shrink away according to the time of the year. For example, before March, at the end of the fiscal year, the availability of nursing staff is very limited. This means that the spouse or family member who is caring for someone in the home must take time off work and risk losing income.

This year, the Canadian Palliative Care Association decided to concentrate its efforts on calling the federal government's attention to the importance of protecting families against the often disastrous consequences of agreeing to care for a family member in the home. We know that this can lead to a loss of jobs, of income, et cetera.

**Senator Pépin:** These people can never take a day off.

**Dr. Lapointe:** No. People of course prefer to remain at home, but when we talk about home care, we imagine an end-of-life health care administration system that will be sufficient and able to cope with the demand seven days a week and 24 hours a day. If there is a crisis at 2:00 a.m., you want to be able to reach something other than voicemail. Within our communities, we need residences for institutions that will recreate a family setting at a lower cost, institutions that will be able to handle crises requiring acute care or even hospitalization. We must think of the Canadians who suffer from degenerative illnesses, such as Alzheimer's disease, who end up in homes where they have no access to palliative care expertise.

**Senator Pépin:** According to your statistics, there is an increase of 21 per cent for people who are dying. It upsets me to see that AIDS agencies were given a million dollars in grants while your association only received \$30,000. Further on, we see that there was an increase in 1998. Can you explain that to me?

**Dr. Lapointe:** The comparison was not meant as a complaint because the Canadian AIDS Association received those amounts but it weighs the grants that were given for the operation's budgets. We are comparing \$30,000 to a million for operating budgets and not for budgets related to specific projects. Of course,

Une de ces raisons est l'absence d'un soignant naturel, un membre de la famille disponible et capable de prodiguer des soins. Il peut s'agir de la présence du conjoint, de la conjointe ou d'enfants en mesure de soigner. Pensons aux personnes âgées qui vivent dans de petits villages en Gaspésie et dont les enfants vivent en milieu urbain. Pensons aux gens qui vivent isolés au centre-ville et qui ne peuvent voir les membres de leur famille.

Lorsqu'on parle de soins à domicile, il faut savoir qu'il peut y avoir mort à domicile. Les soins à domicile sont souhaitables lorsque les conditions le permettent. Il faut prévoir des alternatives dans les services offerts.

Au Canada, certaines institutions spécialisées dans les communautés recréent un domicile pour les grands malades et des services hospitaliers sont offerts à ceux qui les demandent. Nous savons que les coûts des soins à domicile sont en grande partie assumés par la famille.

La présence de personnel soignant est limitée par des budgets qui, comme une peau de chagrin, rétrécissent selon la période de l'année. Par exemple, avant le mois de mars, à la fin de l'année fiscale, la disponibilité du personnel infirmier est très réduite. Cela signifie que le conjoint ou le membre de la famille qui soigne à domicile doit perdre des jours de travail et la sécurité de revenu n'est pas assurée.

Cette année, à l'Association canadienne des soins palliatifs, nous avons adopté comme objectif principal de communication de souligner au gouvernement fédéral l'importance de protéger les familles contre les conséquences souvent désastreuses d'accepter de soigner un de leurs proches à domicile. Nous savons que cela s'accompagne de pertes d'emploi, de revenus, et cetera.

**Le sénateur Pépin:** Ces personnes ne peuvent jamais prendre congé.

**M. Lapointe:** Non. Le domicile est certes le lieu privilégié de la vie, mais quand on parle de soins à domicile, on pense à un système d'administration des soins de fin de vie efficaces et capables de répondre à la demande sept jour sur sept, 24 heures sur 24. Si une crise survient à deux heures du matin, on ne veut pas faire appel à une boîte vocale. Nous avons besoin, au sein de nos communautés, de résidences ou d'institutions recréant le milieu familial mais à moindres coûts, pouvant faire face à des crises qui nécessitent des soins aigus ou et même une hospitalisation. Il faut penser aux Canadiens atteints de maladies dégénératives, comme l'Alzheimer, qui se retrouvent dans des centres d'accueil et qui n'ont pas accès à l'expertise de soins palliatifs.

**Le sénateur Pépin:** Selon vos statistiques, on note une augmentation de 21 p. 100 des personnes au seuil de la mort. Je suis bouleversée de constater que les agences de lutte contre le sida ont reçu un million de dollars en subventions alors que votre société n'a reçu que 30 000 \$. Un peu plus loin, on voit qu'il y a eu une augmentation en 1998. Pourriez-vous m'expliquer de quoi il s'agit?

**M. Lapointe:** La comparaison ne dénonce pas le fait que la Société canadienne du sida ait reçu de tels montants mais elle pondère les montants des subventions visant les budgets d'exploitation. En ce sens, nous comparons 30 000 \$ à un million pour des budgets de fonctionnement et non pour des budgets liés à

we benefitted, as I indicated, from other sources of funding that allowed us to produce training materials for visiting homemakers and for those who supply palliative care on the street for intravenous drug users. We published documents, courses and curriculum vitae for a number of professionals thanks to this support. Unfortunately, all of the funding is exhausted in completing these projects, and in the meantime, we must survive. Even if the Canadian Palliative Care Association is the only organization that promotes palliative and end-of-life care in Canada, it is having a difficult time at present.

[English]

**Senator Pépin:** My next question I will ask of you both. You say, on page 27, that only 7 of 16 Canadian medical colleges have applied to offer this palliative care program. Do you know the reason for that?

**Dr. MacLachlan:** Perhaps I can use my own medical school as an example. We intend to offer the program starting in the summer of the year 2001 as a one-year program. We have not yet been successful in getting government support for the residents' salaries. In order for a resident to complete that program, he or she would require a salary for that year. It would cost about \$42,000 a year, plus a few other costs of training. We have not yet secured the funding. That is why we did not think we could offer the program for the summer of 2000.

Many other schools are in the same position. We want to offer the program. There is no question that we have the resources and the expertise to do so. We just do not have the support for the residency positions at this point this time. It seems pointless to offer it until we have secured that support.

Does that relate to your situation or to your knowledge of other programs, Dr. Lapointe?

**Dr. Lapointe:** In a few universities, the expertise is simply not available to participate in the residency program of palliative care. We monitor what is going on in the delivery of curriculum. We are particularly concerned with the absence, in the majority of our medical schools, of an undergraduate curriculum in end-of-life care or palliative care beyond communication issues and ethical issues. That means, in a good number of our medical schools, there is no clear curriculum on pain and symptom relief. There is no clear curriculum on end-of-life care, per se. That is worrisome.

**Senator Pépin:** You refer in the brief to the total absence of end-of-life palliative care research from the new Canadian Institute of Health Research.

[Translation]

If I understand correctly, at this time, no research is being done in the area of palliative care?

des projets spécifiques. Bien sûr, nous avons bénéficié, et je l'ai indiqué, de d'autres sources de financement qui ont permis, entre autres, la production de documents de formation pour des auxiliaires familiaux et pour des intervenants qui fournissent des soins palliatifs dans la rue auprès des usagers de drogues intraveineuses. Nous avons publié des documents, des cours et des curriculum vitae pour un ensemble de professionnels grâce à ces soutiens. Malheureusement, il arrive que nous dépensions les fonds au complet dans ces projets, mais entretemps, il faut survivre. Même si l'Association canadienne des soins palliatifs est la seule organisation de promotion des soins palliatifs et des soins de fin de vie au Canada, elle se retrouve actuellement dans une situation très difficile.

[Traduction]

**Le sénateur Pépin:** Ma question suivante s'adresse à vous deux. À la page 27, vous dites que seulement 7 des 16 collèges médicaux canadiens ont présenté une demande pour offrir ce programme en soins palliatifs. Savez-vous pourquoi?

**M. MacLachlan:** Permettez-moi de vous citer l'exemple de ma faculté de médecine. Nous comptons offrir ce programme d'un an à compter de l'été 2001. Nous n'avons pas encore réussi à obtenir l'aide du gouvernement pour rémunérer des médecins résidents. Pour suivre ce programme, un médecin résident devra être rémunéré pendant cette année. Cela coûtera environ 42 000 \$ par an, plus quelques autres dépenses liées à la formation. Nous n'avons pas encore obtenu le financement. C'est pourquoi nous ne pensons pas être en mesure d'offrir le programme pour l'été 2000.

De nombreuses autres facultés sont dans la même situation que nous. Nous voulons offrir ce programme et il ne fait aucun doute que nous disposons des ressources et des compétences voulues pour le faire. Il nous manque simplement l'aide financière pour payer les résidents. Il semble inutile d'offrir ce programme tant que nous n'aurons pas obtenu cette aide.

Est-ce la même chose pour vous ou pour d'autres facultés, à votre connaissance, docteur Lapointe?

**M. Lapointe:** Dans quelques universités, on n'a pas les compétences spécialisées requises pour participer au programme de résidence en soins palliatifs. Nous surveillons la situation dans les programmes d'études offerts. Nous sommes particulièrement inquiets de voir que, dans la majorité des facultés de médecine, on n'offre pas de programme de premier cycle en soins palliatifs ou soins aux mourants, outre des questions de communication et des questions éthiques. Autrement dit, dans bon nombre de facultés de médecine, il n'y a pas de programme véritable sur le contrôle de la douleur et l'allègement des symptômes. Il n'y a pas de programme proprement dit sur les soins à donner aux mourants. C'est inquiétant.

**Le sénateur Pépin:** Dans votre mémoire, vous dites que le nouvel Institut canadien de recherche en santé ne finance absolument pas les travaux de recherche sur les soins palliatifs en fin de vie.

[Français]

Si je comprends bien, actuellement, aucune recherche n'est faite dans le domaine des soins palliatifs?



**Dr. Lapointe:** If I look at the documentation provided by Canadian institutes, it mentions cancer research, but nowhere is palliative or end-of-life care mentioned. We vigorously seek out and meet with many people who are in a position to influence the development of end-of-life and palliative care institutes in order to have these places concentrated and not spread about here and there according to the institutes' wishes. Of course, when you have to choose between curing people of a disease or making those who are going to die of it more comfortable, traditionally, the decision has always gone one way.

We are quite worried about the lack of willingness to create an institute for end-of-life or aging care where concerns for palliative or end-of-life care could be clearly addressed.

[English]

**Dr. MacLachlan:** The research of the Canadian Institute for Health Research often tends to be disease-specific, focusing on diseases such as AIDS or cancer. We all will die but not all of us will die of AIDS or cancer. Many of us will die from heart disease or in the emergency department. Many will die in critical-care units. Many will die of lung disease, not necessarily cancer-related. If we tend to focus on disease, rather than on the process of dying, then palliative care does not get adequate recognition. That is a real problem with the mandate of CIHR.

[Translation]

**Senator Beaudoin:** Dr. Lapointe, you say that everyone is in favour of palliative care and that we should have national standards. I agree with that because the medical profession is the same everywhere.

But as someone who is in charge of a Canadian, federal, movement, et cetera, and who is well aware of the situation in Quebec, do you foresee certain jurisdictional problems in this area? Health can sometimes be a provincial responsibility and sometimes it is federal.

For palliative care, I think that the provinces have a fairly large role to play and we should take that into account in our report. We are all in favour of palliative care and we would all like the federal government to intervene, but do you think there might be a jurisdiction problem?

**Dr. Lapointe:** It is obvious that health care and services are a provincial jurisdiction. That is why this morning I took the time to point out the absence of palliative care, and therefore a lack of leadership, in areas of federal jurisdiction, that is, among other things, in the administration of health care and services on the First Nations reserves, as well as in federal penitentiaries. The federal government has to play a preeminent leadership role and it should begin in its own backyard, as they say in Quebec: on the one hand, it must demonstrate an interest in offering health care and services in Canada penitentiaries for inmates who are living with cancer or AIDS and, on the other hand, on the First Nations reserves, for Aboriginal people and their families who are facing a

**M. Lapointe:** Si vous regardez la documentation fournie par les instituts canadiens, on y parle de recherches sur le cancer, mais nulle part, on n'y fait mention de soins palliatifs ou de soins de fin de vie. De façon très vigoureuse, nous rencontrons de nombreuses personnes capables d'influencer le développement des instituts sur les soins de fin de vie et les soins palliatifs afin que ces lieux soient concentrés et non pas disséminés au bon vouloir de la plupart des instituts. Il est certain que lorsqu'on se retrouve face au choix de la recherche entre guérir les gens d'une maladie ou soulager des gens qui vont en mourir, traditionnellement, le poids a toujours penché d'un côté.

Nous sommes très inquiets de l'absence de volonté à l'égard de la création d'un institut sur les soins de fin de vie ou sur le vieillissement où on retrouverait clairement les préoccupations de soins palliatifs et de soins de fin de vie.

[Traduction]

**M. MacLachlan:** Les recherches de l'Institut canadien de recherche en santé sont souvent axées sur une maladie précise, par exemple le sida ou le cancer. Nous mourrons tous un jour, mais nous ne mourons pas tous du sida ou du cancer. Bon nombre d'entre nous mourrons d'une maladie du cœur ou au service d'urgence. Bon nombre mourront dans les services de soins intensifs. Bien des gens mourront d'une maladie pulmonaire, mais pas nécessairement liée au cancer. Si nous nous concentrons trop sur une maladie plutôt que sur le processus de la mort, on n'accorde pas assez d'importance aux soins palliatifs. C'est un véritable problème compte tenu du mandat de l'institut.

[Français]

**Le sénateur Beaudoin:** Docteur Lapointe, vous dites que tout le monde est en faveur des soins palliatifs et que l'on devrait se doter de standards nationaux. Je pense bien que c'est vrai, parce que la médecine est la même partout.

Mais vous qui êtes à la tête d'un mouvement canadien, fédéral, et cetera, et qui connaissez très bien la situation au Québec, envisagez-vous dans ce domaine certains problèmes de juridiction? La santé est du ressort provincial ou fédéral selon ses aspects.

Pour les soins palliatifs, j'ai bien l'impression que les provinces ont un assez grand rôle à jouer et nous devons en tenir compte dans notre rapport. Nous sommes tous favorables aux soins palliatifs et nous voulons tous que le gouvernement fédéral intervienne, mais y voyez-vous un problème de juridiction?

**M. Lapointe:** Il est certain que l'administration de soins et de services de santé est une compétence provinciale. C'est d'ailleurs pourquoi je me suis attardé ce matin à vous souligner l'absence de soins palliatifs, donc une absence de leadership, dans les domaines de juridiction fédérale, c'est-à-dire entre autres dans l'administration de soins et de services de santé dans les réserves des Premières nations, de même que dans les pénitenciers fédéraux. Le gouvernement fédéral doit jouer un rôle proéminent de leadership et il commence dans sa propre cour, comme on dit au Québec: d'une part, il doit manifester un intérêt à dispenser des soins et des services dans les pénitenciers canadiens pour les personnes incarcérées qui vivent avec un cancer ou le sida et,

terminal illness and who require end-of-life care that is specific to their culture.

**Senator Beaudoin:** And the armed forces?

**Dr. Lapointe:** Thank you for reminding me; in military hospitals as well. Then, there are health promotion roles that are the responsibility of the federal health department. For example, Health Canada is responsible for the training of professionals, through its support for the development of national standards.

Do you remember, some years ago, when geriatrics was becoming an emerging practice in Canada? A number of doctors said that they practised geriatrics because they cared for a number of elderly people. It is not because you are caring for the dying that you are offering palliative care and it does not mean that you have the necessary knowledge or expertise to care for these people. Anyone can say that they do, but as long as there are not standards for best practices, then we have a problem.

The federal health department also has a role to play in post-secondary education and research. Grants would obviously allow for the emergence of a critical mass of researchers and professors in medical and nursing schools as well as in other professional institutions of learning.

Therefore I would say that yes, there are jurisdictions, and each of our provincial associations is lobbying. I can tell you, for example, that the Quebec Association will be submitting an important and imposing report in the coming weeks during a provincial tour where we have checked on the availability of services as they exist in each region, indicating the status for each of these regions. The association will be submitting a strategic plan to the minister that is aimed at correcting the deficiencies that we have noted throughout the province of Quebec. Each of our provincial associations will be undertaking this lobby, however, within the federal government, there are a number of areas for which the federal health department is responsible.

**Senator Beaudoin:** I wholeheartedly agree with you when you say that both levels of government are responsible for a number of areas depending on the sector.

[English]

My second question is addressed to Dr. MacLachlan. Part of our mandate is centred on withdrawing, withholding and the Criminal Code, because the Criminal Code is a federal statute. Since our 1995 report, has anything of significance happened at the judicial level in either of those areas? The law is always evolving. We regularly amend the Criminal Code of Canada. Our Criminal Code is good, but nothing is perfect, therefore, we must amend it from time to time. There are also cases before the courts. Our judicial system is very strong and, in my opinion, accurate.

Over the last five years I did not notice many cases that touched on those two issues, but I know there must have been some. You told us that the charges were dismissed in the *Morrison* case. That happened in your own province. In other provinces we had

d'autre part, dans les réserves des Premières nations, pour les autochtones et leurs familles qui font face à une maladie terminale pour accorder des soins de fin de vie qui leur sont culturellement spécifiques.

**Le sénateur Beaudoin:** Et les militaires?

**M. Lapointe:** Merci de me le rappeler, dans les hôpitaux militaires également. Ensuite, il y a des rôles de promotion de la santé qui appartiennent au ministère fédéral de la Santé. Par exemple, la formation des professionnels relève du ministère de la Santé, par le biais du soutien au développement de normes nationales.

Souvenez-vous, il y a quelques années, lorsqu'on essayait d'implanter la gériatrie comme pratique émergente au Canada. De nombreux médecins disaient pratiquer la gériatrie parce qu'ils soignaient des personnes âgées. Ce n'est pas parce qu'on soigne des mourants qu'on offre des soins palliatifs et qu'on a les connaissances et l'expertise nécessaire pour soigner ces personnes. Tous peuvent le prétendre, mais tant et aussi longtemps que des normes et des standards de pratique n'édicte pas les «best practices», nous avons un problème.

Il y a aussi le rôle du ministre fédéral de la Santé dans l'éducation postsecondaire et la recherche. Il est certain que des subventions permettraient l'émergence d'une masse critique de chercheurs et d'enseignants dans les écoles de médecine, de nursing et autres écoles professionnelles.

Donc d'emblée, oui, il y a des juridictions et chacune de nos associations provinciales forment un lobby. Je peux vous informer, par exemple, que l'association québécoise remettra au cours des prochaines semaines un rapport assez important et imposant sur une tournée provinciale où nous avons vérifié la disponibilité des services telle que vécue dans chacune des régions, avec un état de la situation de chacune de ces régions. Elle proposera à la ministre un plan stratégique pour pouvoir combler les lacunes que nous avons notées sur l'ensemble du territoire québécois. Ce lobby est assuré par chacune de nos associations provinciales, mais il y a toutefois, au gouvernement fédéral, amplement de champs de compétence qui relèvent du ministre fédéral de la Santé.

**Le sénateur Beaudoin:** Je suis tout à fait d'accord avec vous, à savoir que les deux paliers de gouvernement ont beaucoup de champs de compétence selon les secteurs.

[Traduction]

Ma deuxième question s'adresse au Dr MacLachlan. Une partie de vos activités portent sur l'interruption et la non-initiation de traitement et le Code criminel, car il s'agit d'une loi fédérale. Depuis la publication de notre rapport en 1995, y a-t-il eu des progrès importants au niveau juridique dans l'un de ces deux domaines? La loi est en évolution constante. Nous modifions régulièrement le Code criminel du Canada. Notre Code criminel est bon, mais rien n'est parfait; il faut donc le modifier de temps à autre. Il y a également des procès devant les tribunaux. Notre système judiciaire est très solide et, à mon avis, exact.

Au cours des cinq dernières années, je n'ai remarqué que peu de procès en rapport avec ces deux questions, mais je sais qu'il doit y en avoir eu certains. Vous nous avez dit que dans l'affaire *Morrison*, les poursuites ont été abandonnées. Cela s'est passé



jurisprudence of the court of first instance, in the Court of Appeal and, in the Supreme Court of Canada with the *Rodriguez* case. What developments have there been in those two particular areas in the last five years, that is, withdrawal and withholding of treatment?

**Dr. MacLachlan:** The difference from 1994 to the year 2000 is that there is a clear understanding among health providers that it is ethically supported and legal to either withdraw life-sustaining treatment or withhold the treatment. There are guidelines for that and, as I mentioned, the best approach is to discuss it with the patient, ideally when they are able to give directions as to what they would wish. Failing that, you have discussions with the family members. However, it is very clear, from both the courts and professional standards of practice, that we are not obligated to offer futile treatment. That is very clear.

There have been a couple of legal speed bumps. There was one situation in Winnipeg where the courts ordered reinstatement of the need to undertake cardiopulmonary resuscitation, but that was subsequently dropped after extensive discussion with the family. I believe that was more a communication issue. That was one case that caused us some concern that, indeed, the courts were going to override statements by health-care providers that cardiopulmonary resuscitation in that case would be futile.

**The Chairman:** To interject, I believe you are talking about the *Sawatsky* case.

**Dr. MacLachlan:** Yes.

**The Chairman:** In fact, Dr. MacLachlan, it was not withdrawn. The patient died. His wife was still pursuing that legal action against the hospital at the time of his death.

**Dr. MacLachlan:** Thank you for that clarification.

That did give us a bit of a jolt because we had been working on the understanding that we were clear, we were in keeping with your report on withholding and withdrawal of treatment, that that was an accepted professional standard where care was futile and ideally where this followed the wishes of the patient or the family.

With respect to the withdrawal, withholding of therapy, I do not think there is much controversy in the country. I believe that is accepted as a standard where you can demonstrate futility and, ideally, that you have the assent of the patient or the family.

**Senator Beaudoin:** We were unanimous on those two points and I believe we were also unanimous on the guidelines. The guidelines, in my opinion, are very important. They may perhaps vary from year to year, to a certain extent, because this is the way we legislate in our country. We try to improve legislation. In my opinion, that is the role of the Senate.

dans votre province. Dans d'autres provinces, il y a la jurisprudence du tribunal de première instance, de la Cour d'appel et de la Cour suprême du Canada dans l'affaire *Rodriguez*. Y a-t-il eu une évolution quelconque dans ces deux domaines au cours des cinq dernières années, c'est-à-dire en ce qui a trait à la non-initiation ou à la cessation de traitement?

**M. MacLachlan:** La différence entre 1994 et l'an 2000, c'est que les fournisseurs de soins savent désormais qu'il est acceptable, sur le plan éthique et juridique, d'interrompre ou de ne pas entreprendre un traitement à l'égard d'une personne mourante. Il existe des directives à ce sujet et, comme je l'ai déjà dit, la meilleure façon de faire est d'en discuter avec le patient, idéalement lorsqu'il est en mesure de donner des directives quant à ce qu'il souhaite. À défaut de cela, on peut en discuter avec les membres de la famille. Toutefois, il est très clair, tant d'après les décisions des tribunaux que d'après les normes de pratiques professionnelles, que nous ne sommes pas obligés d'offrir un traitement inutile. C'est très clair.

Il y a eu quelques bosses de ralentissement au niveau judiciaire. Dans un cas, à Winnipeg, les tribunaux ont ordonné le rétablissement du besoin de procéder à la ressuscitation cardiopulmonaire, mesure à laquelle on a renoncé par après consécutivement à une discussion exhaustive avec la famille. Je crois que c'était là beaucoup plus une question de communication. Ce cas nous a causé de l'inquiétude dans la mesure où, en effet, les tribunaux allaient se substituer aux soignants qui disaient que la ressuscitation cardiopulmonaire dans ce cas-là serait inutile.

**La présidente:** Permettez-moi d'intervenir, je crois que vous parlez de l'affaire *Sawatsky*.

**M. MacLachlan:** Oui.

**La présidente:** En fait, docteur MacLachlan, il n'y a pas eu cessation du traitement. Le patient est décédé. Sa femme avait entamé des poursuites judiciaires contre l'hôpital au moment de son décès.

**M. MacLachlan:** Je vous remercie de cette clarification.

Cela nous a donné un coup, comme qui dirait, parce que nous étions partis de l'idée que tout était clair, que nous nous conformions à votre rapport sur l'abstention et l'interruption de traitement, que c'était une norme professionnelle admise dans les cas où tout traitement était inutile et où, idéalement, une telle mesure était respectueuse des vœux du patient ou de la famille.

Pour ce qui est de l'abstention ou l'interruption de traitement, je ne crois pas que cela suscite de grandes controverses au pays. Je crois que c'est une norme admise, dans les cas où l'on peut démontrer que tout traitement est inutile et que, idéalement, on a le consentement du patient ou de la famille.

**Le sénateur Beaudoin:** Nous étions unanimes sur ces deux points, et je crois que nous étions également unanimes relativement aux lignes directrices. À mon avis, les lignes directrices sont très importantes. Elles peuvent peut-être varier d'une année à l'autre, dans une certaine mesure, parce que telle est la manière dont nous légiférons dans notre pays. Nous tâchons d'améliorer les lois. À mon avis, c'est là le rôle du Sénat.

Are you aware of any case that has improved the situation in that particular area?

**Dr. MacLachlan:** I am not aware of any case that has improved the situation. The *Sawatsky* case has caused us to be cautious.

The implementation of the first recommendations from your 1995 report would be very helpful for some clarity on this issue. We could then support the third recommendation to develop professional guidelines to match the amended Criminal Code.

**Senator Corbin:** Dr. MacLachlan, in your paper you spoke about ethics and morality. What distinction do you make between the two?

**Dr. MacLachlan:** There is a subtle distinction. We have our own set of moral values that drive individual behaviour. Morals are more individual and drive behaviour. Ethics is more a pooling of those moral values, trying to come up with a societal norm. Both can be dynamic. However, ethics is more a global reflection of society's moral thinking at the time.

**Senator Corbin:** I was a member of the earlier committee and heard, among others, a witness from Montreal who spoke about ethics. That particular witness said that, in this day and age, you do not tell young medical students how to ethically conduct themselves. Those may not be the exact words. The meaning of that statement was that you set out in a broad way what medical ethics is all about, but then individual medical practitioners interpret ethics in a clinical environment in whatever way they wish.

My question is: If there is such a thing as a medical ethical code, how strictly is it adhered to by individuals? Is there room for wide interpretation? Does a person's sense of morality come into play in these situations, or is it strictly cold, clinical ethics?

You referred a number of times in your paper to your guidelines, which I do not assimilate to be the same as morality or ethics. What are the barriers? What are the common fringes between the various notions? Ultimately, how does a doctor in a clinical situation resolve these conundrums?

**Dr. MacLachlan:** Our reference point for ethics, as far as the practice of medicine, is probably best reflected in the code of ethics that comes from the Canadian Medical Association that has been in place for over 100 years but is revised frequently. Its last revision was four years ago.

If you asked me where is my reference point today for decision making, it would be a brochure that I have on the wall in my office and in all my examining rooms which is the CMA code of ethics. It is helpful to know what that body has stated. My college and the Royal College of Physicians and Surgeons have endorsed the code.

Êtes-vous au courant de cas où l'on aurait amélioré la situation dans ce domaine particulier?

**M. MacLachlan:** Je ne suis au courant d'aucun cas qui aurait amélioré la situation. L'affaire *Sawatsky* nous a incités à la prudence.

La mise en oeuvre des premières recommandations de votre rapport de 1995 clarifierait bien des choses dans ce domaine. Nous pourrions alors soutenir la troisième recommandation visant à mettre au point des lignes directrices professionnelles qui concorderaient avec le Code criminel modifié.

**Le sénateur Corbin:** Docteur MacLachlan, dans votre texte, vous parlez d'éthique et de morale. Quelle distinction tracez-vous entre les deux?

**M. MacLachlan:** C'est une distinction subtile. Le comportement individuel est encadré par un ensemble de valeurs morales. Les valeurs morales sont davantage axées sur l'individu, et elles guident le comportement. L'éthique constitue beaucoup plus une mise en commun de ces valeurs morales, à partir desquelles on essaie d'établir une norme sociétale. Les deux peuvent être dynamiques. Cependant, l'éthique reflète beaucoup plus la pensée morale d'une société à une époque donnée.

**Le sénateur Corbin:** J'ai siégé au premier comité et j'ai entendu, entre autres, un témoin de Montréal qui parlait d'éthique. Ce témoin disait qu'à notre époque, on n'impose plus de code d'éthique aux jeunes étudiants de médecine. Ce n'est peut-être pas ce qu'il a dit exactement. Ce qu'il voulait dire, c'est que l'on définit de manière générale l'éthique médicale, et de là, chaque praticien de la médecine interprète l'éthique dans un milieu clinique de la manière qu'il veut.

Voici ma question: existe-t-il un code d'éthique médicale, et dans quelle mesure chaque praticien y adhère-t-il? Y a-t-il de la place pour une interprétation large? Est-ce que le sens moral d'une personne intervient dans ces situations, ou applique-t-on strictement une éthique froide, clinique?

Vous mentionnez plusieurs fois dans votre texte vos lignes directrices, que je n'assimile pas à la morale ou à l'éthique. Quels sont les obstacles? Quels sont les points communs entre ces diverses notions? Comment un médecin en situation clinique résout-il finalement ces difficultés?

**M. MacLachlan:** Notre meilleure référence déontologique, en ce qui concerne la pratique de la médecine, s'exprime probablement dans le code de déontologie de l'Association médicale canadienne, lequel existe depuis plus de 100 ans et est révisé fréquemment. Sa dernière révision remonte à il y a quatre ans.

Si vous me demandez sur quoi je me fonde aujourd'hui pour prendre des décisions, je vous dirai qu'il s'agit d'une brochure affichée au mur de mon bureau et au mur de toutes mes salles d'examen, une brochure qui donne le code de déontologie de l'AMC. Il est utile de savoir ce que cet organisme préconise. Mon collège et le Collège royal des médecins et chirurgiens du Canada ont avalisé ce code.



That is perhaps the best reference point from which we might determine ethical professional behaviour in this case. Unfortunately, these tend to be general statements, such as: That I am not to denigrate the reputation of my colleagues, but I am to report unprofessional activity to the appropriate authorities. However, would that apply in the case of a physician who I felt was not prescribing medications appropriately? Very general types of statements tend to come from the code of ethics.

We then take those and develop guidelines for clinical practice and for professional activity in specific areas. That is what we are trying to do with the statement on euthanasia and assisted suicide. We wanted to reflect the current code of ethics of the Canadian Medical Association and apply it to the areas of assisted suicide and euthanasia. We had hoped to demarcate what was ethical practice, what was good clinical practice, and what are practices that are clearly illegal at this point in time in Canada.

There is a significant amount of information available, particularly from the report. My worry is that, if you were to ask any of the 55,000 doctors in Canada today for the best reference point for statements about the intent of treatment and alleviating suffering and what if it advances death, not many would have "Of Life and Death" in their bookcases. That is regrettable; it is a very well written document.

We wanted to take reference points that we felt were clear and develop them into guidelines for physicians to use from February 2000 as a reference point in patient care. Our goal was to take the code of ethics as well as reference documents such as yours, and develop a practical aid for physicians to use in making clinical decisions.

One of the things we raised with you in November 1994, was that we operate in a patient-doctor dyad. We tend to have individual decisions to be made in clinical care based on an individual patient, that patient's own moral framework, environment, their wishes, and their family's wishes. That is the locus of our operation is a one-on-one dyad with a patient and their family in their environment and context.

The law may not be particularly helpful in a one-on-one dyad. We do not want to urge health care providers to break the law, but the law must apply to the country. We must operate on a one-on-one dyad with you and your family. That is why we need guidelines that are perhaps more explicit, but we cannot advocate activities that are clearly illegal. That is why we have been trying to say to physicians: "Beyond this point is illegal. Do not go there."

I am not sure if I answered your question, Senator Corbin.

**Senator Corbin:** The presentations this morning were substantial in terms of ethics, morality, philosophy and what life and death are all about. I am not in a position right now to admit

C'est peut-être le meilleur point de départ pour déterminer ce qui constitue une ligne de conduite professionnelle dans ce cas. Malheureusement, il s'agit plutôt d'énoncés généraux tels que: Je ne dois pas dénigrer la réputation de mes collègues, mais je dois faire rapport de toute activité non professionnelle au responsable approprié. Toutefois, est-ce que cela s'applique dans le cas d'un médecin qui à mon avis ne prescrit pas les médicaments appropriés? Les codes de déontologie ont tendance à offrir des énoncés très généraux.

À partir de ces généralités, nous élaborons des directives qui visent la pratique clinique et les activités professionnelles d'un domaine précis. C'est ce que nous tentons de faire avec cette déclaration sur l'euthanasie et l'aide au suicide. Nous voulions refléter ce qui se trouve dans le code de déontologie actuel de l'Association médicale canadienne et appliquer ces mêmes principes à l'aide au suicide et à l'euthanasie. Nous espérons faire une distinction entre la pratique professionnelle, une bonne pratique clinique et ce que nous considérons des pratiques clairement illégales, en ce moment au Canada.

On trouve de nombreux renseignements, surtout dans le rapport. Je crains que si l'on demandait à n'importe quel des 55 000 médecins au Canada aujourd'hui quel est le meilleur endroit où trouver des écrits sur l'objet des soins et l'allègement de la souffrance et sur la possibilité d'abrégier la vie, ils ne seraient pas nombreux à avoir dans leurs étagères «De la vie et de la mort». C'est déplorable; c'est un document très bien rédigé.

Nous avons voulu choisir des points de référence qui à notre avis étaient clairs et les travailler pour en faire des lignes directrices à l'intention des médecins à compter du mois de février 2000 pour le soin des malades. Notre objectif consistait à prendre un code de déontologie ainsi que des documents de référence, tels que votre rapport, et d'élaborer un guide pratique dans les décisions cliniques à l'intention des médecins.

Un des aspects que nous avons soulevés avec vous en novembre 1994, c'est le fait que nous nous trouvons en présence d'une dyade patient-médecin. Nous devons prendre des décisions au cas par cas dans le soin des patients en tenant compte du cadre moral du patient, de son environnement, de ses souhaits et de ceux de sa famille. Voilà le site de notre intervention dans une relation un à un avec un patient et sa famille dans leur environnement et contexte.

La loi n'est pas particulièrement utile dans une telle situation de un à un. Nous ne voulons pas encourager les fournisseurs de soins de santé à enfreindre la loi, mais la loi doit s'appliquer à l'échelle du pays. Nous devons fonctionner en relation un à un avec vous et votre famille. Voilà pourquoi il nous faut des lignes directrices peut-être un peu plus claires, mais nous ne pouvons pas préconiser des activités qui sont clairement illégales. Voilà pourquoi nous essayons de dire aux médecins: «Au-delà de ce point, c'est illégal. Ne le faites pas».

Je ne sais pas si j'ai répondu à votre question, monsieur le sénateur Corbin.

**Le sénateur Corbin:** Les exposés de ce matin étaient importants du point de vue de la déontologie, de la moralité, de la philosophie et des questions de vie et de mort. Je ne suis pas en

that I have absorbed all of the statements. I certainly wish to reflect upon them. I may write to the witnesses to ask them to clarify some of their statements.

I rapidly read the editorial. What I get from it is that things are evolving constantly. Medicine must re-adjust itself to standards, ethics and so on. You are doing that and that is positive. You are trying to help your membership and the general public.

Parliament, unfortunately, in my opinion, has refused to address this matter front on. This committee must tell the governments, Parliament, and assemblies, that these bodies are not assuming their responsibility. One of the most frustrating things following the presentation of our report was that very few people moved the way they ought to have moved.

**Dr. MacLachlan:** To pursue your comment in the context of what I referred to earlier, there is no question that at my hospital, following the arrest of Dr. Nancy Morrison, our approach to pain control was very different. I am not sure we are back to where we were, much less at the current standard.

It was a shock to everyone that a physician who seemed to be wanting to care for a patient and alleviate suffering — I will not get into the specifics of the case, but it seems to most of us who know something of the case that the intent was to alleviate suffering — would be charged with murder. I think the repercussions of that case, although the charges have been dropped, have not yet been forgotten. I would urge you to proceed with a very important task to give us the clarity we need.

**Senator Roche:** This question is in the form of a comment to Dr. MacLachlan, not excluding Dr. Lapointe if he wishes to join in this. Like Senator Pépin, I was neither a senator nor a member when the committee compiled this report. Since I did not participate in it, I feel freer than perhaps my colleagues do to say it is an excellent report.

**Dr. MacLachlan:** It is.

**Senator Beaudoin:** We agree with you.

**Senator Roche:** I thought you might. I am always looking for agreement.

Although it has taken a little while, I think I have finally figured out what this committee is all about. I am sitting here asking myself why the recommendations on palliative care, pain control and advanced directives and so on have not been taken seriously by the government. The testimony of both our witnesses this morning is a devastating comment on the inaction by the government.

That leads me to conclude that, while palliative care as a centrepiece of this discussion this morning is a growing social need in our country, it is not on the political agenda, and I must ask myself why. Dr. MacLachlan, in your last comment to Senator Corbin, you touched on what is on my mind, and that is the confusion in the public mind and the government's sensitivity to shying away from yet one more controversial question in our society. I think that it is the public's inability or hesitation in differentiating between bona fide palliative care and all that it

mesure actuellement de dire que j'ai absorbé tout ce qui a été dit. Je tiens certainement à y réfléchir. J'écrirai peut-être aux témoins pour leur demander de préciser certaines de leurs affirmations.

J'ai lu l'éditorial rapidement. J'en conclus que les choses évoluent constamment. La médecine doit se réadapter aux normes, à la déontologie, etc. Vous le faites, c'est encourageant. Vous tentez d'aider vos membres et la population.

Malheureusement, à mon avis, le Parlement a refusé de s'attaquer à cette question. Notre comité doit dire aux gouvernements, au Parlement et aux assemblées législatives qu'ils n'assument pas leur responsabilité. L'une des choses les plus exaspérantes constatées après la publication de votre rapport, c'est que très peu de ceux qui auraient dû réagir l'ont fait.

**M. MacLachlan:** Pour répondre à votre commentaire dans le contexte que j'ai mentionné plus tôt, il ne fait aucun doute qu'à mon hôpital, après l'arrestation du Dr. Nancy Morrison, notre approche au contrôle de la douleur a été très différente. Je ne suis pas certain que nous en soyons revenus là où nous étions, encore moins au niveau des normes actuelles.

Ce fut un choc pour tous qu'un médecin qui semblait vouloir soigner un patient et soulager la douleur — je ne vais pas entrer dans les détails de l'affaire, et il semblait à la plupart d'entre nous qui connaissent un peu l'affaire que l'intention était de soulager la douleur — soit accusé de meurtre. Les répercussions de cette affaire, bien qu'on ait retiré les accusations, n'ont pas encore été oubliées. Je vous exhorte à aller de l'avant et à nous donner les précisions dont nous avons besoin.

**Le sénateur Roche:** Ma question se veut un commentaire au Dr. MacLachlan mais cela n'empêche pas le Dr. Lapointe d'y répondre s'il le souhaite. Comme le sénateur Pépin, je n'étais ni sénateur ni membre lorsque le comité a préparé ce rapport. Et puisque je n'ai pas participé aux travaux du comité, je suis peut-être un peu plus libre que mes collègues de dire que c'est un excellent rapport.

**M. MacLachlan:** En effet.

**Le sénateur Beaudoin:** Je partage votre avis.

**Le sénateur Roche:** C'est bien ce que j'avais pensé. Je cherche toujours l'entente.

Bien qu'il m'ait fallu un peu de temps, je pense avoir enfin compris la raison d'être de ce comité. Je suis assis là à me demander pourquoi le gouvernement n'a pas pris au sérieux les recommandations sur les soins palliatifs, le contrôle de la douleur et les directives préalables, etc. Le témoignage de nos deux témoins ce matin constitue une condamnation percutante de l'inaction du gouvernement.

J'en conclus donc que bien que les soins palliatifs qui étaient au cœur de la discussion de ce matin représentent un besoin social croissant au pays, cette question n'est pas à l'ordre du jour politique, et je me demande pourquoi. Docteur MacLachlan, dans votre dernier commentaire au sénateur Corbin, vous avez parlé d'une chose à laquelle je pensais, c'est-à-dire la confusion dans l'esprit du public et la tendance du gouvernement à esquiver une fois encore une question controversée dans la société. Je pense que c'est l'incapacité ou l'hésitation de la population à faire une



takes into account, which includes the voluntary termination of life-sustaining medical equipment, assisted suicide and involuntary euthanasia.

I am not presenting this as any definitive analysis, but I wonder if the government, in receiving this report, noted that the committee itself was divided on the questions of assisted suicide and involuntary euthanasia. I wonder if that division drew the attention of those government persons, whether in the justice department or finance — I hope we will hear from them in due course — and sapped their attention, thus reducing the attention they paid to the unanimous conclusions of the report. If I may put it in crude terms, the committee was divided because some wanted a "gutsier" reaction by the government than the very important steps that needed to be taken. Both our distinguished witnesses this morning have said society is suffering as a result of the almost indiscernible government action toward what the committee felt was necessary to enhance the life condition of those in a terminal illness.

I suppose Senator Carstairs and her colleagues were right in saying that this time we should get a report that deals with what was unanimous in 1995. They advocated a report going forward to the government that presses the government to take action on what we are all agreed on, and which has been highlighted here this morning, and that is palliative care. Perhaps this time the government will listen.

Dr. MacLachlan, you said in referring to the fallout from the *Morrison* case that it made the persons in your profession "gun-shy", if I may use that term, about steps that they could take. It probably made them gun-shy in approaching the government. In other words, everyone is going soft on hitting the government hard on palliative care and home care and everything that goes with that because they are afraid of being misinterpreted as advocates for involuntary euthanasia or assisted suicide.

Assisted suicide advocates and involuntary euthanasia advocates get so much publicity in the country. This has resulted in a public interpretation of the issue that has brought us to this table this morning on the topic of assisted suicide rather than palliative care.

The palliative care advocates are being tarred by the assisted suicide advocates. I put that to you, but not as a definitive analysis for I have not been here long enough. Please give me your opinion of my thinking.

**Dr. MacLachlan:** You have given it a lot of thought. There was very helpful comment in the report early on in the definition section that attempted to clarify the difference among euthanasia, assisted suicide, and withholding of treatment. Euthanasia was described as being the causation of death; assisted suicide being assisting with the death; and withholding/withdrawal of therapy

distinction entre des soins palliatifs en bonne et due forme et tout ce que cela comporte, y compris le débranchement de l'équipement essentiel au maintien de la vie, l'aide au suicide et l'euthanasie involontaire.

Je ne prétends pas qu'il s'agit d'une analyse définitive, mais je me demande si le gouvernement, lorsqu'il a reçu ce rapport, a noté que les membres du comité étaient divisés sur la question de l'aide au suicide et de l'euthanasie involontaire. Je me demande si cette division a attiré l'attention des représentants gouvernementaux au ministère de la Justice ou des Finances — j'espère que nous en entendrons parler au moment opportun — et si cela n'a pas détourné leur attention et ainsi réduit l'attention qu'ils ont donnée aux conclusions unanimes dans ce rapport. En termes plus crus, les membres du comité étaient divisés parce que certains voulaient que le gouvernement réagisse avec plus de cran pour prendre les mesures très importantes qu'il faut prendre. Nos deux distingués témoins de ce matin ont affirmé que la société souffre à cause de l'inaction du gouvernement qui n'a pas pris les mesures que le comité jugeait nécessaires pour améliorer la condition de vie des malades en phase terminale.

Je suppose que le sénateur Carstairs et ses collègues avaient raison de dire que cette fois-ci, il faut un rapport qui porte sur ce qui avait été convenu à l'unanimité en 1995, un rapport qui exhorte le gouvernement à prendre des mesures sur ce que nous préconiserons tous et dont il a été question ce matin, c'est-à-dire les soins palliatifs. Cette fois-ci le gouvernement écoutera peut-être.

Docteur MacLachlan, vous avez mentionné les retombées de l'affaire *Morrison*, disant que les membres de votre profession étaient apeurés si on peut dire, et craignaient de prendre les mesures qu'ils étaient appelés à prendre. Cela les a probablement empêchés d'approcher le gouvernement. En d'autres termes, tout le monde met des gants de velours pour exercer des pressions sur le gouvernement en ce qui concerne les soins palliatifs et les soins à domicile et tout le reste parce qu'on craint d'être mal interprété et d'être vu comme préconisant l'euthanasie involontaire ou l'aide au suicide.

Les défenseurs de l'aide au suicide et de l'euthanasie involontaire reçoivent beaucoup de publicité dans notre pays, ce qui nous a amenés ici ce matin, à cette table, pour parler du suicide plutôt que des soins palliatifs à cause de l'interprétation que la population fait de cette question.

Les défenseurs des soins palliatifs sont assimilés aux défenseurs de l'aide au suicide. J'avance ces idées, non pas comme une analyse définitive, parce que je ne suis pas ici depuis assez longtemps, mais j'aimerais savoir ce que vous pensez de mes idées.

**M. MacLachlan:** Vous avez manifestement beaucoup réfléchi à la question. On trouve au début du rapport une liste de définitions où l'on tente de préciser la différence entre l'euthanasie, l'aide au suicide et l'abstention de traitement. On y décrit l'euthanasie comme un acte qui provoque la mort; l'aide au suicide comme aider quelqu'un à se donner la mort; et

being watching death unfold, if I can paraphrase the definition section.

You are correct in thinking that we are, perhaps, confusing good palliative care practices with assisted suicide. That is why I wanted to highlight what seemed to me to be one of the more crucial actions that you recommended in 1995. The Criminal Code should be revised to match your very clear statement in the document that providing treatment aimed at alleviating suffering that may shorten life is legal. You made a very clear statement and went on to reflect in chapter 4 that perhaps the Criminal Code needed to be amended to be explicit on that. You alluded to the fact that we do need urgent action on that, so that palliative care does not get tarred with the brush of assisted suicide and euthanasia. We would all agree with what you are advocating in your statement.

Good palliative care is appropriate treatment for alleviating suffering. It may hasten death. In many cases, that has been overstated. Appropriate treatment with narcotics and opioids may not hasten death and may actually prolong life because a person is under less stress because they have less pain.

You are very apt in saying that we, perhaps, have done palliative care a disservice by not being clear about what we are advocating in your statement that treatment aimed at alleviating suffering which may shorten life is legal. A very clear statement on that and, perhaps, changes in the Criminal Code might have meant that we would not have had to agonize over the *Morrison* case.

**Dr. Lapointe:** I, too, wish to comment on the non-intended effect, that is, providing a patient with adequate and appropriate medication to relieve his pain or other symptoms could hasten his death. In most cases, it will prolong the life of the patient. It is a vastly exaggerated risk. I believe it is a myth. In fact, the risks attached to the use of morphine or other strong narcotics, and other drugs of that nature, in the proper hands and administered with the expertise we have gained over the last 30 years of the existence of the palliative care field is extremely rare. I use the word "extremely" knowing that it is the case that it will hasten death, that it will provoke the double effect. In fact, the fear that exists among physicians in using those drugs to relieve that pain and the fear that they might be accused of hastening death, as well as the fear among family members concerning those drugs, prevents the proper relief of pain and causes the suffering of many, many patients in this country. There is a role here for the Senate to dispel that myth. Too much emphasis on the double effect has itself a double effect which has a negative impact on the patient.

**The Chairman:** I have a number of practical questions that I want to put to both of you. When we did our original study, the figure we heard over and over again was that 5 per cent of dying patients had access to genuine palliative care. For the most part, they tended to be cancer patients because of the pain associated

l'abstention de traitement ou l'interruption de traitement comme le fait de cesser de maintenir le patient en vie, si je paraphrase correctement les définitions.

Vous avez raison de penser que peut-être nous confondons les bonnes pratiques de soins palliatifs et l'aide au suicide. C'est pourquoi je tenais à mettre en relief ce qui me semble l'une des mesures essentielles que vous avez recommandées en 1995. Il faut revoir le Code criminel en fonction de l'énoncé très clair dans votre rapport où vous dites qu'il est légal d'administrer un traitement destiné à soulager la souffrance au risque d'abrégé la vie. Vous l'avez énoncé très clairement en ajoutant au chapitre IV que peut-être faudrait-il modifier le Code criminel afin de le dire clairement. Vous faites allusion au fait qu'il nous faut intervenir de façon urgente pour que les soins palliatifs ne soient pas assimilés à l'aide au suicide ou à l'euthanasie. Nous convenons tous de ce que vous préconisez là.

Les bons soins palliatifs sont les soins qui conviennent pour soulager la douleur. Cela peut abrégé la vie. Dans de nombreux cas, on a exagéré ce phénomène. Les soins appropriés au moyen de narcotiques et d'opioïdes n'abrègent pas nécessairement la vie, au contraire, puisqu'une personne qui a moins de stress a moins de douleur.

Vous avez tout à fait raison de dire que peut-être avons-nous mal servi les soins palliatifs en ne précisant pas clairement ce que nous préconisons en disant qu'il est légal d'administrer des traitements destinés à soulager la souffrance au risque d'abrégé la vie. Un énoncé clair et peut-être aussi des modifications au Code criminel auraient peut-être permis d'éviter l'angoisse provoquée par l'affaire *Morrison*.

**M. Lapointe:** J'aimerais moi aussi parler de l'effet involontaire, c'est-à-dire qu'en donnant des médicaments adéquats et appropriés à un patient afin de soulager sa douleur ou d'autres symptômes, on peut précipiter sa mort. Dans la plupart des cas, ces médicaments prolongeront la vie du patient. Le risque est très exagéré. C'est un mythe. En fait, il est extrêmement rare qu'il y ait des risques rattachés à l'utilisation de la morphine ou d'autres narcotiques puissants ou drogues de cette nature lorsqu'ils sont administrés par des personnes expérimentées capables de compter sur les connaissances acquises au cours des 30 dernières années dans le domaine des soins palliatifs. Je dit «extrêmement rare» en sachant qu'il y a des cas où ces produits précipiteront la mort, que l'effet sera double. En fait, la crainte existe chez les médecins qui utilisent ces drogues pour soulager la douleur car ils craignent d'être accusés d'avoir précipité la mort, tout comme ils craignent que les préoccupations des membres de la famille du patient face à ces drogues les empêchent de soulager la douleur et provoquent des souffrances chez de nombreux patients au Canada. Le Sénat doit détruire ce mythe. En accordant trop d'importance à l'effet double, cela provoque en soi un effet double qui a des répercussions néfastes sur le patient.

**La présidente:** J'ai plusieurs questions pratiques que je veux vous poser. Lorsque nous avons fait notre étude initiale, on nous a dit encore et encore que 5 p. 100 des mourants avaient accès à de véritables soins palliatifs. Pour la plupart, il s'agissait de patients atteints de cancer parce que dans de nombreux cas, la mort par



with death by cancer in many instances. Is that number still valid, or has it increased or decreased?

**Dr. Lapointe:** I will admit that we do not have the data to answer your question. I referred earlier to a one-year study of the situation in Quebec. What we encountered is that everyone admits to performing palliative care. Thus, when you ask a health centre if it has a palliative care program, the answer is "yes". However, when you ask whether they have specific people working in the program, the number of affirmative responses decreases. When you ask if they have a program to detect people in the family who are at high risk of pathological bereavement reaction, then a small proportion of those who answered "yes" in the first place were able to say "yes".

I cannot really say if the 5 per cent number appropriate. All I know is that it is a minority of Canadians. If you are looking at cancer patients, patients with Alzheimer's and other degenerative diseases, you will see an absence of palliative care and end-of-life care with trained professionals in the majority of nursing homes in this country. We do not have in our hands at the moment the statistics that you ask about, Madam Chair.

**The Chairman:** You talked about the financial and emotional burdens borne by families who look after a person dying within the home. You made particular reference to the very elderly who I suspect partly because they have no one on whom to be a burden but who, because of their own wish not to be a burden, actually choose the option of dying in a hospital. Do you have any data on the health consequences to a person looking after a dying person?

My own personal experience tells me that my mother probably would have lived many years longer, despite her deteriorating heart condition, if she had not been for 10 years the principal care worker for her husband, a stroke victim, a brittle diabetic and suffering from a number of other ailments.

Do you have any data on that?

**Dr. Lapointe:** There is some research data that I could provide which shows, for instance, that the bereaved, or the recently bereaved, are at higher risk of health problems. In fact, a good number of the recently bereaved will consult a physician for a health problem that is directly related to the bereavement or the recent loss.

Presently, we have underway research projects looking at the quality of life of family members and caregivers in Montreal and in other centres across the country. In time, we will be able to report the results to you. Those are very important questions as we are devolving more and more of the responsibility of the care to people who find themselves very ill equipped, most of the time, to take care of a loved one.

A study done in Canada showed that the successful death at home was connected to one's financial means. That is to say you could grant the wish of your loved one to die at home, if you had the money to contract for private services.

cancer est très douloureuse. Est-ce que ce chiffre est toujours valable, a-t-il augmenté ou diminué?

**M. Lapointe:** Je dois avouer que je n'ai pas les données pour répondre à votre question. J'ai parlé plus tôt d'une étude d'un an sur la situation au Québec. Nous avons constaté que tous déclaraient offrir des soins palliatifs. Ainsi, si vous demandez à un centre de santé s'il y a un programme de soins palliatifs, on répond «oui». Toutefois, si vous demandez si du personnel précis est affecté à ce programme, le nombre de réponses affirmatives diminue. Lorsque vous demandez si le centre a un programme de détection des membres de la famille qui ont un risque élevé d'avoir une réaction pathologique au deuil, alors un petit pourcentage de ceux qui avaient d'abord répondu «oui», sont toujours en mesure de dire «oui».

Je ne saurais dire si 5 p. 100 est le chiffre exact. Tout ce que je sais, c'est que c'est une minorité de Canadiens. Si vous regardez les patients atteints de cancer, d'Alzheimer et d'autres maladies dégénératives, vous constatez l'absence de soins palliatifs, l'absence de soins de fin de vie offerts par des professionnels dans la majorité des foyers pour personnes âgées du pays. Nous n'avons pas en mains les statistiques que vous demandez, madame la présidente.

**La présidente:** Vous avez parlé du fardeau financier et émotif des familles qui s'occupent d'un mourant à domicile. Vous avez parlé tout particulièrement des personnes très âgées qui, j'en ai l'impression, parce qu'elles n'ont personne pour s'occuper d'elles ou parce qu'elles souhaitent ne pas être un fardeau, choisissent de mourir à l'hôpital. Avez-vous des données sur les séquelles pour la santé de la personne qui s'occupe d'un mourant?

Ma propre expérience me dit que ma mère aurait probablement vécu de nombreuses années de plus, malgré une maladie cardiaque qui s'aggravait, si elle n'avait pas été pendant 10 ans la principale responsable des soins à son mari, victime d'un accident cérébrovasculaire, diabétique insulino-dépendant et souffrant de plusieurs autres maladies.

Avez-vous des données à ce sujet?

**M. Lapointe:** Je pourrais vous fournir certaines données de recherche qui démontrent par exemple que les personnes en deuil, ou en deuil depuis peu, courent un risque plus élevé de problèmes de santé. En fait, bon nombre de personnes dont le deuil est récent consultent un médecin pour des problèmes de santé directement liés au deuil ou à la perte récente d'un être cher.

Nous poursuivons en ce moment des projets de recherche qui examinent la qualité de vie des membres de la famille et des soignants à Montréal et dans d'autres centres au pays. Avec le temps, nous devrions pouvoir vous faire part des résultats. Ce sont là des questions très importantes car nous confions de plus en plus la responsabilité des soins à des personnes qui, bien souvent, sont mal préparées pour prendre soin d'un être cher.

Une étude effectuée au Canada révèle que la réussite dépendait des moyens financiers si l'on voulait qu'un être cher meurt chez lui. C'est-à-dire que vous pourriez accéder au souhait d'un être cher de mourir à domicile si vous aviez les moyens financiers de retenir des services privés.

**Dr. MacLachlan:** It is always worrisome to add an anecdote, but in this case it may be relevant. In talking with a doctor who provides a consulting service out of the Royal Victoria Hospital he related to me circumstances involving a home visit he made last week to a 54-year-old man who is caring for a 93-year-old mother at home. She has end-stage Alzheimer's disease and has not been able to communicate for 10 years. She was maintained at home with the help of live-in help paid for by himself and receiving 24-hour-a-day care. It took about three hours per meal to feed her the pureed food which she eats. Her care was impeccable. However, the son said that he could not go on providing this care. He said, "I have spent 10 years doing this. This is not my mother. This is a mere memory of what my mother was. Please help me. Is there anything we can do at home?" He was told by the doctor that there was no way the doctor could help him, and he explained why. The son said, "I can understand that, but I think then we are going to have to admit her to a nursing home or hospital." He went on to say, "And I bet she will be dead within two weeks." The sad thing is that due to cutbacks and other things, he is probably right.

Your point is very apt in terms of bringing forward the burden on family givers. I do not want to cloud things with one anecdote, but you have raised a number of important points. There is an indirect burden on caregivers who provide unofficially supported palliative care at home.

**The Chairman:** Dr. Lapointe, you said that it is an enormous cost financially — forgetting for the moment the emotional cost — to look after a seriously ill patient in the home environment. Currently, the tax system does not address that issue. It is addressed better in Quebec than in other provinces but, in my experience, essentially the issue is not addressed. As well, we have made no provision which deals with those who give up their jobs — primarily women — to look after a terminally ill family member.

Is that your understanding of the situation?

**Dr. Lapointe:** You are totally correct in saying, first, that the burden of care is mainly shouldered by the women of this country who find themselves caring for their parents and often for the parents of their spouse, and who are left wondering who will care for them.

Second, there are really no provisions at present, either fiscally at the federal level or through security-of-income legislation, that protect family members in this country. This is something we need to do. We need to change rapidly if we are to, at the very least, not create a disincentive for home care. If it is possible, home, as I mentioned, is the place where people would live, so let us not create negative incentives to home care. Let us change the system and change all those laws and regulations in order to provide better security and certainly not plunge a family into debt or into being at risk of losing their home or so on, which is the case at present.

**M. MacLachlan:** C'est toujours ennuyeux d'ajouter une anecdote, mais dans ce cas-ci, c'est peut-être pertinent. J'ai parlé à un médecin qui offre des services de consultation à l'hôpital Royal Victoria. Il m'a raconté les circonstances d'une visite à domicile qu'il a faite la semaine dernière à un homme de 54 ans qui prend soin de sa mère de 93 ans à la maison. Elle est en stade terminal de la maladie d'Alzheimer et est incapable de communiquer depuis 10 ans. Elle demeure à la maison avec l'aide de personnel payé par son fils et reçoit des soins 24 heures sur 24. Il faut environ trois heures par repas pour la nourrir de la purée qu'elle mange. Ses soins sont impeccables. Toutefois, son fils dit qu'il ne peut plus fournir ces soins. Il dit: «Ça fait 10 ans que je fais cela. Ce n'est pas ma mère. C'est simplement le souvenir de ma mère. Veuillez m'aider. Y a-t-il quelque chose que nous pouvons faire à la maison?» Le médecin lui a dit qu'il ne pouvait pas l'aider et lui a expliqué pourquoi. Le fils a répondu: «Je comprends, mais je pense que nous allons devoir la placer en foyer ou à l'hôpital». Il a ajouté: «Je parierais qu'elle sera morte dans les deux semaines.» Le malheur, c'est qu'à cause des réductions budgétaires et du reste, il a probablement raison.

Vous faites valoir un argument très juste à propos du fardeau imposé aux membres des familles qui dispensent les soins. Je ne veux embrouiller les choses avec des anecdotes, mais vous avez mentionné un certain nombre d'arguments importants. Il existe un fardeau indirect pour ceux qui donnent des soins palliatifs à la maison sans aide officielle.

**La présidente:** Docteur Lapointe, vous dites qu'il coûte extrêmement cher — sans parler pour l'instant du coût émotif — de soigner à domicile un patient gravement malade. À l'heure actuelle, il n'existe pas de dispositions à cet égard dans le régime fiscal. La situation est meilleure au Québec que dans d'autres provinces, mais d'après mon expérience, il n'existe pas de dispositions dans ce domaine. Il n'existe pas non plus de dispositions pour aider les personnes qui renoncent à leur emploi, surtout des femmes, pour s'occuper d'un membre de leur famille qui souffre d'une maladie mortelle.

Est-ce bien ce que vous constatez aussi?

**M. Lapointe:** Vous avez tout à fait raison lorsque vous dites que les soins sont surtout dispensés par les femmes, qui se retrouvent obligées de s'occuper de leurs parents et souvent des parents de leur conjoint et qui se demandent à leur tour qui prendra soin d'elles.

Deuxièmement, il n'existe à l'échelon fédéral aucune disposition fiscale ou des dispositions sous le régime de la loi sur la sécurité du revenu pour protéger les membres des familles au Canada. Ce sont des mesures qu'il faudrait adopter. Il faudrait agir rapidement pour éviter, à tout le moins, de décourager les gens de se faire soigner à domicile. Comme je l'ai dit, les gens préfèrent vivre dans leur foyer, si c'est possible, et il faudrait éviter de décourager les soins à domicile. Modifions le système, toutes les lois et les règlements, afin d'accroître la sécurité et d'éviter que certaines familles doivent s'endetter au risque de perdre leur maison, entre autres, comme c'est actuellement le cas.



If I remember correctly, the Canada Health Act was enacted to prevent the fact that disease would financially destabilize a family and compromise its hope for a good life. What we are facing at the present is that the one member of the family living with a life-threatening illness is provoking that very thing we hoped to avoid with the creation and the enactment of the Canada Health Act. We need to move quickly to correct this.

**The Chairman:** Finally, there was an aspect of your presentation that confused me. Perhaps you could clarify it. At one point, you implied that in one of our recommendations — and I was not sure whether it was with respect to withholding or withdrawing or pain treatment — we may have made the situation worse rather than better by our recommendation. Would you elaborate on that?

**Dr. MacLachlan:** I was referring to the first recommendation in chapter 4 under pain control and sedation practices where the committee recommended that the Criminal Code be amended to clarify the practice of providing treatment for the purpose of alleviating suffering that may shorten life. The difficulty I have is that, although there is some supporting text in the section, it does not specify what amendments you felt would be necessary in order to clearly support the statements you made on page 31, with which I think all our bodies agree, where you say that you recognize that providing treatment aimed at alleviating suffering that may shorten life is legal. It is a clear, crisp, direct statement. Then when I read your first recommendation, I wondered, if it is that clear and legal, what particular amendments require to be made to the Criminal Code? You need to know, of course, that I am coming from the land of *Morrison*, so I may be more twitchy than others, but it was not clear from your report what specific sections needed to be amended to make it absolutely explicit that your earlier statement was accurate. That is where the confusion lies. It was not that I was questioning in any way what you were saying, but if you found inadequacies in the Criminal Code, it would have been very helpful if you had identified what they were and addressed them. I hope that clarifies my remark.

**The Chairman:** I understand where you are coming from.

**Senator Beaudoin:** I would like to make one point on that. If pain is being experienced, it should be alleviated. I have no problem with that. Of course, the person may die earlier than expected, but the purpose of the treatment is to alleviate the pain. The purpose of the committee recommendation was that the situation should be made clear in the Criminal Code. We were informed that some doctors and nurses and some people generally do not know exactly where the law stands on this. In a democratic society, we need laws that are as clear as possible. This might have been the reason we worded our recommendations as we did.

Of course, although a committee of the Senate may prepare a report, the decision to make changes is up to the government. The government will do what it wants to do, at the time it wants to do it. The Criminal Code is amended often, and it can be done again.

Si je me souviens bien, la Loi canadienne sur la santé a été adoptée pour éviter que des familles puissent être déstabilisées financièrement par la maladie et perdent ainsi tout espoir de vie prospère. À l'heure actuelle, lorsqu'un membre d'une famille souffre d'une maladie qui menace sa vie, nous nous trouvons dans cette situation que nous espérons éviter en adoptant la Loi canadienne sur la santé. Nous devons agir rapidement pour corriger cette situation.

**La présidente:** Enfin, il y a un aspect de votre présentation que je n'ai pas bien compris. Vous pourriez peut-être me l'expliquer. Vous avez dit quelque part que dans l'une de nos recommandations — et je ne suis pas certaine s'il s'agissait de l'abstention ou l'interruption de traitement ou des traitements contre la douleur —, nous avons empiré les choses plutôt que de les améliorer. Pourriez-vous nous en dire davantage à ce sujet?

**M. MacLachlan:** Ce dont j'ai parlé, c'est de la première recommandation au chapitre 4, au sujet des pratiques en matière de traitement de la douleur et de sédation. Le comité recommandait que le Code criminel soit modifié afin de clarifier la situation concernant l'administration d'un traitement destiné à soulager la souffrance au risque d'abrégé la vie. Ce qui me dérange, dans cette recommandation, c'est que malgré le texte qu'on trouve à son appui dans le chapitre, le comité ne précise pas quels amendements il estime nécessaires pour appuyer vos déclarations de la page 33, que tous nos organismes approuvent, c'est-à-dire: «Le comité reconnaît qu'administrer un traitement destiné à soulager la souffrance au risque d'abrégé la vie est légal.» C'est une déclaration claire et nette. Quand j'ai lu votre première recommandation, je me suis demandé quelles modifications il faudrait apporter au Code criminel, si ces traitements sont légaux. Je vous signale que je viens de la région où a eu lieu l'affaire *Morrison* et que je suis peut-être plus chatouilleux que d'autres à ce chapitre, mais votre rapport ne précisait pas quels articles devaient être modifiés pour préciser de façon absolue l'exactitude de votre déclaration. C'est là que c'est embrouillé. Je ne mettais pas en doute ce que vous avez dit, mais si vous trouvez qu'il y a des lacunes dans le Code criminel, il aurait été utile que vous les identifiiez et que vous proposiez des correctifs. J'espère que cela précise ma remarque.

**La présidente:** Je comprends.

**Le sénateur Beaudoin:** Permettez-moi un commentaire à ce sujet. S'il y a de la souffrance, il faut la soulager. J'en conviens. Le patient mourra peut-être plus tôt que prévu, mais le but du traitement, c'est de soulager la douleur. Ce que le comité a recommandé, c'est que ce soit clair dans le Code criminel. On nous a dit que certains médecins et des infirmiers et infirmières, et d'autres gens en général, ne savent pas exactement l'état de la loi à ce sujet. Dans une société démocratique, les lois doivent être aussi claires que possible. C'est peut-être pour cette raison que nous avons libellé notre recommandation de cette façon.

Mais évidemment, même si un comité du Sénat prépare un rapport, c'est au gouvernement qu'il incombe d'apporter les changements. Le gouvernement fait ce qu'il veut, quand il le veut. Le Code criminel est modifié fréquemment et il peut l'être de

However, the purpose of legislation is to improve the wellbeing of society and that might be achieved by amending the Criminal Code.

It is good if doctors, nurses and all those involved in the health system do not know exactly what their rights are and what the law is. It is part of our duty here in the Senate and the House of Commons — the Parliament of Canada — to legislate as clearly as we can.

**Dr. MacLachlan:** Yes. I think you are correct there. In your first recommendation, where you stated that the Criminal Code should be amended to clarify the practice of providing treatment for the purpose of alleviating suffering that may shorten life, perhaps if you had added a couple of words at the end to ensure that it would be clear that this practice is legal, it would have been better. A few words at the end of that recommendation might have alleviated my anxiety.

**Senator Beaudoin:** We may improve that. The sky is the limit.

**The Chairman:** I thank you both for being with us this morning.

I was pleased to hear that Senator Roche now seemed to understand exactly what it is we are trying to do this time around, which gave me some hope for the whole study. We want to focus on what it is that there was no disagreement upon, so that we can bring the government, quite frankly, to account for their lack of action; and to not obfuscate the issues in any way, because there were some recommendations about which we were not unanimous.

Honourable senators, our meeting is adjourned.

The committee adjourned.

nouveau. Toutefois, le but des lois est d'améliorer le sort de la société, et il est possible pour cela de modifier le Code criminel.

Si les médecins, les infirmiers et infirmières et tous les participants au régime de soins de santé ne connaissent pas exactement leurs droits et l'état des lois, c'est nécessaire. C'est le devoir du Sénat et de la Chambre des communes — du Parlement du Canada — d'adopter des lois aussi claires que possible.

**M. MacLachlan:** Oui. Vous avez raison. Dans votre première recommandation, où vous dites que le Code criminel devrait être modifié afin de clarifier la situation concernant l'administration d'un traitement destiné à soulager la souffrance au risque d'abréger la vie, il aurait peut-être mieux valu ajouter quelques mots à la fin, pour indiquer qu'un tel traitement est légal. Il aurait suffi de quelques mots à la fin de cette recommandation pour atténuer mes craintes.

**Le sénateur Beaudoin:** Nous pouvons améliorer cela, rien n'est impossible.

**La présidente:** Merci à tous les deux d'être venus nous rencontrer ce matin.

Je suis heureuse de constater que le sénateur Roche semble maintenant comprendre exactement ce que nous essayons de faire. Cela me donne de l'espoir pour notre étude. Ce que nous voulons examiner, ce sont les éléments sur lesquels il n'y avait pas de désaccord afin que nous puissions amener le gouvernement à reconnaître qu'il n'a rien fait; nous ne voulons pas embrouiller les choses, car il y a eu des recommandations qui n'ont pas fait l'unanimité.

Honorables sénateurs, la séance est levée.

La séance est levée.









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WITNESSES—TÉMOINS

*From the Canadian Palliative Care Association and the  
Association québécoise de soins palliatifs:*

Dr. Bernard Lapointe, President.

*From the College of Family Physicians of Canada:*

Dr. Richard MacLachlan, Head, Faculty of Medicine,  
Dalhousie University.

*De l'Association canadienne des soins palliatifs et de l'Associa-  
tion québécoise de soins palliatifs:*

M. Bernard Lapointe, président.

*Du Collège des médecins de famille du Canada:*

M. Richard MacLachlan, directeur, faculté de médecine,  
Université Dalhousie.



Français

# Proceedings of the Subcommittee to Update "Of Life and Death"

**Second Session Thirty-sixth Parliament, 1999-2000**

*Chair:* The Honourable SHARON CARSTAIRS

Tuesday, February 22, 2000

## Issue No. 3

Third meeting on: Examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death"

- [Minutes of Proceedings](#)
- [Transcript \(Evidence\) of Proceedings \(121K\)](#)

## WITNESSES:

### **From the Royal College of Physicians and Surgeons:**

Dr. Michel Brazeau, Chief Executive Officer;

Dr. Henry Dinsdale, Past President, National Council on Ethics in Human Research.

### **From the Canadian Pharmacists Association:**

Mr. Jeff Poston, Executive Director.

### **From the Canadian Healthcare Association:**

Sharon Sholzberg-Gray, President and Chief Executive Officer.

### **From the Canadian Medical Association:**

Dr. Gordon L. Crelinsten, Chair, Committee on Ethics.

### **From the Canadian Nurses Association:**

Sharon Nield, Manager, Nursing Policy and Regulatory Support.





## MEMBERS OF THE SUBCOMMITTEE

The Honourable Sharon Carstairs, *Chair*

The Honourable Gérald-A. Beaudoin, *Deputy Chair*

and

The Honourable Senators:

\*Boudreau, P.C. (or Hays), Corbin, Keon, \* Lynch-Staunton (or Kinsella), Pépin

\* *Ex Officio Members*

(Quorum 3)

### **Changes in membership of the committee**

Pursuant to rule 85(4), membership of the committee was amended as follows:

The name of the Honourable Senator Corbin substituted for that of the Honourable Senator Kirby  
(*February 21, 2000*).

The name of the Honourable Senator Kirby substituted for that of the Honourable Senator Corbin  
(*February 16, 2000*).







Français

# Proceedings of the Subcommittee to Update "Of Life and Death"

## Issue 3 - Evidence

OTTAWA, Tuesday, February 22, 2000

The Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 9:08 a.m. to examine the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death."

Senator Sharon Carstairs (*Chairman*) in the Chair.

[*English*]

The Chairman: Today is our third day of hearings under our mandate to update the unanimous recommendations of the 1995 Special Senate Committee Report on Euthanasia and Assisted Suicide entitled "Of Life and Death." I remind honourable senators and, most particularly, the witnesses that this committee is not reopening the debate on assisted suicide and euthanasia. It is dealing strictly with the areas of the report in which the original committee made unanimous recommendations. I ask everyone to bear this in mind as we proceed.

Today we have five witnesses who have been invited to address us on the issue of palliative care: Dr. Michel Brazeau, who is accompanied by Dr. Henry Dinsdale, Dr. Gordon Crelinsten, Sharon Shlozberg-Gray, Jeff Poston and Ms Sharon Nield.

Dr. Michel Brazeau, Chief Executive Officer, Royal College of Physicians and Surgeons: Madam Chair, thank you for your invitation. I am a medical microbiologist and infectious disease physician and chief executive officer of the Royal College of Physicians and Surgeons of Canada. I am not an expert in medical ethics. I am accompanied, however, by Dr. Henry Dinsdale, former president and executive director of the Royal College of Physicians and Surgeons of Canada, and former president of the National Council on Ethics in Human Research. I consider him to be very much an expert on the question of ethics. He is here to assist me in responding to your questions.

I intend first to speak briefly about the Royal College; I do not miss an opportunity to do so. I will then go on to some general statements on the issues before us and then pursue, with some specific comments, the chapters from the previous recommendations.

The Royal College of Physicians and Surgeons of Canada is an organization of 32,000 medical specialists dedicated to ensuring the highest standards and quality of health care. The Royal College





accredits the residency training programs in all 16 faculties of medicine in Canada. The college also grants certificates in 53 specialties and subspecialties and two special programs, including one in palliative medicine.

I will immediately point out that I have provided notes from my presentation, documents about the Royal College, and also documents published by the college since 1995 on the issues before you. There are also a number of excerpts from our annals from fall 1999 that deal specifically with bioethics for clinicians.

Recently the Royal College has become much more involved in the organization and delivery of health care services. The college recognizes that it cannot set the standards for the training of medical specialists without becoming intimately involved in defining and determining the environment in which they practise. We at the Royal College are convinced that we are in a period of in-depth renewal of the health care system in Canada, which will take some years. We are not simply repairing the system.

To become and remain fellows of the Royal College, our certificants must maintain their professional development, publicly demonstrated, and pledge to uphold the highest standards of professional behaviour. The payment of annual dues by our members and the remarkable volunteer contributions of over 1,500 of them, up to 40 days per year, allow the college to fulfil its mission, which is largely educational.

As many other such colleges are finding throughout the world, this is a time when we must re-engage in a fundamental aspect of our role -- ethics as an important part of professional behaviour.

The Royal College has adopted the code of ethics of our colleagues at the Canadian Medical Association. These guidelines spell out the rules and principles applicable to each of our members in his or her professional activity. However, our biomedical ethics committee and administrators of the college are now studying emerging ethical issues that include the collective responsibilities of physicians, the public, and governments in the social contract that binds us all. The organization of Canadian health care services lends itself to the study of this particular topic.

Is there any need to remind ourselves of the change in our perceptions from 1990 to 2000? In 1990, the focus was on the oversupply of physicians and nurses and the over-utilization of the system. Today, it has shifted to shortages of physicians and nurses and the potential under-utilization of health care services caused by reduced access -- both major concerns for the public.

Since 1996, the Royal College has clearly distinguished between the general competencies of the medical specialist and those that are specific to each specialty. Our CanMEDS 2000 project defines the core competencies for Canadian specialty physicians as those of medical expert, communicator, collaborator, manager, health advocate, scholar, and professional. It is the development of the latter role that enables medical specialists to manage the ethical dilemmas that confront physicians on a day-to-day basis. Specialty-specific educational objectives will provide medical specialists with the competencies needed, for example, to optimize their recourse to the available arsenal of modern therapeutics to manage pain.

As a last general comment, the Royal College strongly suggests that the Canadian Institutes of Health Research be involved as a fundamental resource in dealing with many of the issues.

We now review some of the chapters containing recommendations from June 1995.

First, we thank you for the opportunity to draw to your attention the new, one-year program of added





competence in palliative care that is accredited jointly by the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada. The accreditation standards of these programs are appended to your documents. Four programs have already been approved by the Royal College at the universities of Alberta, Manitoba, McGill, and Laval. Requests from McMaster, Ottawa, and Montreal universities are presently under review.

Unfortunately, training programs in palliative medicine have not been adequately funded until now. Also the infrastructure and the means to provide adequate palliative care, to ensure enough health professionals are trained, to inform the public, and to conduct much-needed research are severely lacking. The needs of an ageing population for palliative care are constantly increasing. The incidence of cancer is rising and many other circumstances warrant increased access to palliative care services. The time period during which palliative care services are provided to individual patients must be extended. It is not enough to provide this type of care only at the moment of death.

I should like to take this opportunity to give you some appreciation of the perceptions of some of our members on palliative care and the current situation. I should like to quote first from Dr. John Seely, on the recommendation that governments make palliative care programs a top priority in the restructuring of the health care system.

Absolutely nothing has been done to address this at the Federal or Provincial level. As far as I know, there is no national strategy on palliative or end-of-life care, nor has there been any attempt in any of the provinces to make palliative care programs a top priority.

It is perhaps worth adding that the needs for palliative/end-of-life care are likely to increase substantially in the coming years as a result of a number of factors: increasing number of elderly persons (both in absolute numbers and as a proportion of the population), increasing prevalence of cancer and increasing application of palliative care to non-cancer patients (e.g. patients with end stage organ failure, ALS, AIDS, and patients who decide to discontinue dialysis), while every study that I am aware of has documented significant unmet needs for simple pain and symptom control in terminally ill patients in acute-care institutions, long term/chronic care institutions or ambulatory settings, in addition to unaddressed psychosocial, emotional and spiritual needs.

Modern palliative care services were established in Great Britain in 1967. Many of our eminent Canadian specialists have commented that our American colleagues have more than made up for their early delays and are a shining example of what can be accomplished with determination and appropriate means. Let us follow in their footsteps.

Adequate access to quality palliative care services would have a positive impact on several of the other issues in the Senate subcommittee's report. We believe the five recommendations drafted in 1995 on palliative medicine are still very valid and more than ever applicable.

Chapter 4 concerns pain control and sedation practices. The 1995 report acknowledged that providing treatment aimed at alleviating pain and suffering that may shorten life was legal. On the other hand, the report recommended that the Criminal Code be clearer on this issue. We believe that the focus should be placed on information and education rather than on such a change.

The second and fourth recommendations in this chapter proposed that Health Canada develop the guidelines and standards for the provision of treatment to alleviate suffering where it may shorten life and for the practice of total sedation of patients. This task was to be carried out in collaboration with the provinces and territories and national professional associations. The Royal College recommends that this





point be reconsidered. Health Canada should play an important supportive role, but the major responsibility for this lies clearly with the professional associations working with the public.

Regarding the third recommendation in this chapter, on education and training in pain control, the Royal College acknowledges its own responsibility in this matter. Thus, the college will use its powerful levers in the accreditation, certification and professional development of specialists. A greater understanding of the laws that regulate health care delivery will be at the forefront of our discussions for integration into our educational objectives.

Chapter 5 concerns withholding and withdrawal of life-sustaining treatment. In light of the clinical experience of the last five years, the need to modify the Criminal Code may be much less than previously anticipated. The specialized teams probably have more power to analyze each situation, make decisions and take appropriate action. Nowadays, communications with patients and their families are more direct and open. Greater access to consultants in ethical matters greatly assists caregivers in their work. We reiterate our previous comment on the participation of Health Canada in the development of clinical guidelines.

As to chapter 7, on assisted suicide, the majority of the recommendations remain valid to us and should be acted upon.

Chapter 8 concerns euthanasia. The Royal College considers the 1995 recommendations still valid, except perhaps for the need to modify the Criminal Code. Although this issue is clearly contentious, the medical specialists we have consulted believe there is no convincing need for modification at this time.

In conclusion, the implementation of the 1995 recommendations on palliative care must remain a high priority for all. The Royal College remains committed to enhancing the quality of training for medical specialists in relation to the issues that are encompassed within your document.

The Chairman: Thank you.

Mr. Jeff Poston, Executive Director, Canadian Pharmacists Association: I thank you for this opportunity to appear today. The Canadian Pharmacists Association is the national voluntary organization representing pharmacists in all areas of practice in Canada.

In approaching the process of reviewing and updating the committee's recommendations, we went back to the pharmacists with whom we spoke in 1995 and inquired of them how they have seen things change at the grassroots in everyday pharmacy practice in the hospital and in the community. If we revisit some of our recommendations relating to palliative care at that time, a number of positive trends seem to be emerging.

First, we see young graduates in medicine, pharmacy, and nursing who are more familiar with palliative care in general and having an improved level of knowledge. There also seems to be some evidence that family caregivers, physicians, nurses, and pharmacists have been working more and more as a team in this area. The consumers themselves, the general public, seem to have greater access to information relating to the issue of palliative care in general.

However, there are many areas that appear to remain of concern. Generally, without any major crises to bring the issue to public attention in the mainstream media, it seems to have lost profile and is not much of a focus for debate.





If we are to make progress in this area, the Senate committee may wish to consider a public opinion survey, and further work with the public to ascertain what consumers are thinking on this issue.

We see that home palliative care is far from being considered an integral part of our health care system. Funding cuts and jurisdictional issues have prevented the expansion of the health continuum to address home care and palliative care, to be able to provide symptom control, symptom relief, and pain control for patients so that they can die with dignity in the comfort of their own homes with their families and loved ones around them.

Current manpower shortages in health care professions make it difficult for the system to find sufficient providers of palliative care services, particularly on a home care basis and in the community.

Our poll of pharmacists across the country found that there are major provincial variations in the availability of palliative care and in access to those services. In some provinces, access varies from region to region, and there are certainly significant differences between rural and urban communities.

Funding remains a critical issue. The fact that access to some drugs is not covered, and the cost of drugs, force people to make difficult choices. In provinces with high deductible or co-pays in drug plans for seniors, patients have to consider whether they can afford expensive medications for control of symptoms, and some patients have been reported as foregoing treatment because of their fear of leaving their spouses destitute.

We see an increase in situations where patients have been admitted to hospital in order to receive medications free of charge, as a way of ensuring that symptom control and palliative care can be provided at the end of life.

We have certainly seen a trend in the development and growth of our knowledge with respect to pain control and sedation practices. New medications, more experience with using a variety of medications, and a greater willingness by practitioners to prescribe those medications in the provision of care to terminally ill patients have been recognized. Our members still report that there is resistance by some, particularly older, practitioners to prescribing the level of opioids needed to ensure that relatively pain-free end of life.

We have seen developments. My colleague from the Royal College of Physicians and Surgeons talked about total sedation. The term used in the literature is "terminal sedation". These are areas in which we have seen developments. I have appended to our brief a recent paper that provides the pharmacists' perspective on terminal sedation.

We welcome recognition of pharmacists' role as drug experts with respect to palliative care. Many protocols have been set in place that allow pharmacists and nurses to adjust the dosage of pain medication for patients receiving palliative care in the hospital or at home.

We have also recognized that many patients and their families appear to be better informed, realizing that they do not have to die in pain, and are becoming more open about asking for terminal sedation, particularly in the hospital situation. Patients and their families appear to be bringing up the issue of terminal sedation earlier than in the past.

We recommend to the committee that terminal sedation and total sedation practices be openly studied to assess their prevalence. This certainly builds on the recommendations that you heard from Dr. Brazeau on the need to work on clinical guidelines in this area.





On the issue of advance directives and living wills, practitioners have indicated to us that they have seen increased use of these over the past five years. Better-informed patients have started to use instruments accessed via the Internet. Although more and more providers are considering these as legally binding, we still hear of cases where patients' families have taken them out of the hospital when providers have indicated that they are not willing to abide by advance directives. Some work still needs to be done, and we recommend that the legal status of living wills or advance directives needs to be formally recognized in many jurisdictions.

I will now move on to the issue of physician-assisted suicide and terminal sedation. Building on the comments I made before, terminal sedation is an area where we do see the need for some further research. There is a suggestion that this is an issue that CIHR could look at, within that new structure. It is perhaps an area that would be well served by the participation of some of the institutes in that new structure. It is difficult to conduct research relating to the dosage, use and duration of therapy with medication in these sorts of circumstances. There is a need for a case-based approach to research in this area, and we certainly would encourage that that be done.

In our 1995 submission, we provided a list of conditions that we felt would need to be in place if physician-assisted suicide was to be permitted or contemplated in Canada. We should like to draw your attention to the experience in Oregon, where the Oregon Death with Dignity Act legalized a form of physician-assisted suicide. The act was passed at the end of 1997, and there has been some recent evaluation of that initiative. Under the act, terminally ill patients receive prescriptions for self-administered, lethal medications from their physicians.

Senator Corbin: On a point of order, is this not outside the scope of our study? We are dealing now specifically with euthanasia and assisted suicide. I thought your admonition at the beginning of the meeting was clear. We do not want to get involved in that.

The Chairman: Mr. Poston, the point of order is correct. That is outside the scope of the review by this committee. However, I thank you for providing us with the information because it is based on your original presentation and gives us an update. We will be updating certain sections in terms of the information available, although not dealing with the recommendations. From that perspective, it is useful material.

Mr. Poston: That was our intent in submitting it. We wanted to update our previous submission on the topic.

In closing, I should like to reiterate that patients need to be free to make appropriate choices with respect to their end of life. Also, an issue that has been of considerable debate within our profession is the need for providers to be free to refuse to participate in certain procedures on the basis of ethical or moral considerations.

As an association, we are concerned about the great variations in access to and availability of palliative care services across the country. We also believe that, in order to ensure access and portability of health coverage for those services, the provinces need to work on harmonizing the level of service available and expanding it where necessary. The availability of palliative care services should not be a function of where one lives, but of where those services are needed.

The Chairman: Thank you. Now from the Canadian Healthcare Association, Sharon Sholzberg-Gray.

Ms Sharon Sholzberg-Gray, President and CEO, Canadian Healthcare Association: The Canadian





Healthcare Association, known as the CHA, is pleased to appear before your subcommittee. As requested, I will be providing an update on new developments related to the recommendations presented in the Senate's 1995 report entitled, "Of Life and Death."

CHA is the federation of provincial and territorial hospital and health organizations committed to preserving and strengthening Canada's health system. Through our membership, CHA represents regional health authorities, hospitals and health care facilities and agencies that employ approximately 1 million health care providers and serve Canadians across the country. These organizations are governed by trustees who act in the public interest.

CHA's mission is to improve the delivery of health services in Canada through policy development, advocacy, and leadership.

Through our provincial and territorial members, CHA represents a broad continuum of care including hospitals; long-term care facilities; home and community care agencies; community health services; public health; mental health; addiction services; children, youth and family services; housing services; and professional and licensing bodies. Therefore, many of our constituents deal with life-and-death realities on a day-to-day basis.

Our presentation today will focus on providing updates on three types of initiatives: CHA-specific initiatives; collaborative initiatives involving the Canadian Healthcare Association; and other initiatives of which we are aware.

With respect to CHA initiatives, the Senate Committee on Euthanasia and Assisted Suicide recommended that governments make palliative care programs a top priority in the restructuring of the health care system, and that there be an integrated approach to palliative care across care settings. These recommendations will not be completely implemented until we are able to realize the vision of an integrated health care system and until there are adequate levels of funding for this system.

CHA's vision is of a publicly funded health system that provides access to a broad range of comparable health services across Canada. Given that, and our breadth of membership, CHA's policy development and advocacy initiatives tend to focus on system issues. In this context, palliative care is part of the broad continuum of needed services for which CHA is continually advocating.

Some of CHA's current advocacy initiatives are focused on developing a sustainable health care system and ensuring adequate and long-term funding for it. Specifically, CHA's advocacy initiatives encompassing palliative care include "CHA's Framework for a Sustainable Health Care System in Canada, A Discussion Paper." This document outlines seven key components, including responding to the changing health needs of Canadians and realizing the vision of an integrated and innovative health care system.

One of CHA's purposes in developing this document is to encourage and facilitate public discussion and debate regarding our health care system and the necessary components for its sustainability. This document is available on CHA's Web site and will soon be available through our press. I brought copies with me for your information. Palliative care is an integral component of our vision of an integrated and innovative health care system.

Another CHA policy initiative is our brief to the Finance Committee in preparation for the 2000 federal budget. CHA prepared a brief entitled, "Creating a Sustainable Healthcare System for the New Millennium." Copies are available for your information.





I will spend a few minutes reviewing our funding recommendations because adequate funding of the existing health care system and the broader continuum of care is required if palliative care is to receive appropriate resources within the publicly funded system.

CHA believes that funding is needed for an integrated continuum of care, one which provides access to all types of health services; in other words, disease protection, health protection, health promotion, illness treatment and palliative care across the continuum of settings, including the home, the community, and institutions.

Unless all parts of the health care system are developed to their full potential, hospitals will continue to face crises as they strive to accommodate both higher service demands and funding constraints.

As the health care system adapts to change, the devolution of resources away from the traditional institutional infrastructure of hospitals must not imperil access to these needed health care services. Investment in and augmentation of all parts of the continuum of care is needed as we work toward the optimum system of an integrated, patient-centred continuum of care.

The current health care system is in crisis. Without adequate and sustained funding, many important and needed services such as palliative care will once again, or will continue to be, viewed as "boutique" services.

I am sure you have recently heard the word "boutique" applied to services in some of the discussions between the premiers of this country and the federal government on the issue of health. We believe that all of these services are an essential part of the Canadian health care system. None of these so-called "extras" can be termed "boutique".

CHA's funding recommendations include urging the federal government to immediately commit, by April 1, 2000, at least \$1.5 billion to the Canadian health care system in order to stabilize the existing system and lay the foundation for creating a sustainable, accessible, integrated, innovative and publicly funded health care system for the new millennium.

We are also urging the federal government to provide a growth factor or escalator to the cash component of the CHST to ensure the long-term sustainability of our health care system. This growth factor should be introduced by April 1, 2001. Without it, important services will continue to be vulnerable to cost-cutting measures.

In addition, CHA is urging the federal government, in consultation with the provincial and territorial governments and health care organizations, to explore new funding mechanisms for health care. Such mechanisms may enable comparable services across a broader continuum of care to be available to all Canadians.

In the current atmosphere of crisis, it is difficult for health care facilities and agencies across the country to develop and implement innovative services, including appropriate palliative care services.

A third CHA initiative is our board of directors' "Watching Brief." At the annual review of strategic directions in October 1999, our organization's board of directors reaffirmed the need for CHA to maintain a watching brief on palliative care. This includes issues related to supporting informal caregivers and accessibility.

CHA's fourth area of initiatives related to palliative care are our CHA board policies. Over the years,





CHA's board of directors has approved a number of policies related to palliative care services and issues. Since 1994, policies related to palliative care include an updated 1995 joint statement on resuscitative interventions and a 1999 joint statement on preventing and resolving ethical conflicts involving health care providers and persons receiving care, of which I will speak further in a minute or two.

In addition to those specific initiatives, there are a number of collaborative projects related to palliative care in which CHA is an active partner.

In this respect, CHA has been and will continue to be very supportive of other groups who are collaborating on or taking the lead in important palliative care initiatives. The Special Senate Committee on Euthanasia and Assisted Suicide made a number of recommendations regarding the development of guidelines to govern the withholding and withdrawal of life-sustaining treatment, the training of health care professionals in all aspects of palliative care, and the collection of information regarding specific treatments.

I will briefly describe three activities in which the CHA has been recently involved that directly touch on palliative care issues.

The joint statement on preventing and resolving ethical conflicts involving health care providers and persons receiving care was developed cooperatively and approved by the boards of directors of the Canadian Healthcare Association, the Canadian Medical Association, the Canadian Nurses Association, and the Catholic Health Association of Canada. This statement is available through each of the sponsoring associations -- some of them are represented here today -- and is available on all of our Web sites. I have brought some copies for your information.

This joint statement deals primarily with conflicts between the person receiving care, or his or her proxy, and care providers. It offers guidance for the development of policies to prevent and resolve ethical conflicts over the appropriateness of initiating, continuing, withholding, or withdrawing care or treatment.

Another collaborative initiative is the Canadian Palliative Care Association's project entitled, "Palliative Care Training for Support Workers", which is being funded by Health Canada. CHA is pleased to be participating in this important project as a member of the national advisory group. I brought a brief summary for your information. I am sure you will be hearing more about this innovative project from the Canadian Palliative Care Association.

CHA's interest in this project is in ensuring that all providers, including support workers, have access to appropriate training resources and support networks.

CHA and other national groups are also working with the Canadian Institute for Health Information on a home care indicators project that includes indicators related to palliation.

CHA is pleased to be involved in these initiatives, which encourage the development and implementation of key processes and resources related to issues of life and death.

In terms of an update on other initiatives in which CHA is not directly involved, the Senate Special Committee on Euthanasia and Assisted Suicide made a number of recommendations regarding the development of guidelines and standards for palliative care practice. In my written remarks, which I have given to the clerk of the committee, I note that the Canadian Palliative Care Association has received funding from Health Canada to work in this area. I should like to correct that and say that they are still





seeking funding but have not yet received it. In fact, they are seeking funding from private sources as well.

In this connection, I should like to point out that the Canadian Palliative Care Association, whose work we value very much, has not received core funding from Health Canada. Thus, it will be less able in the future to carry on its important work in the palliative care area. I should like to make a plea on their behalf, before this committee, for Health Canada to reinstate core funding for the Canadian Palliative Care Association, and other, similar associations, so that they can carry on their valuable work.

Another recommendation from the Special Senate Committee on Euthanasia and Assisted Suicide referenced respite care as an essential component of an integrated approach to palliative care. The Canadian Healthcare Association has made its members aware of an excellent report available through the Canadian Association for Community Care related to respite care. I am proud to have played a role in this project. Formerly, I was the executive director of the Canadian Association for Community Care.

While there has been some progress in responding to palliative care issues over the past five years, there is still much to be done to ensure that palliative care services are integrated into the Canadian health care system. They need to be adequately funded so that they are available to all Canadians. They should be provided within national standards or guidelines and form part of a national database of health services. They should be supported by training resources for all providers and provide needed respite care. The Canadian Healthcare Association, and our provincial and territorial members, will continue to work with others to develop these needed resources and ensure that they are available across the country to health care organizations, providers, and consumers.

Thank you for the opportunity to appear today.

The Chairman: Thank you, Ms Sholzberg-Gray.

Dr. Gordon L. Crelinsten, Chair, Committee on Ethics, Canadian Medical Association: Madam Chairman, I am a cardiologist in private practice in Montreal and an Associate Professor of Medicine at McGill University. With me today is Dr. John Williams, Ph.D., Director of Ethics, Canadian Medical Association.

*[Translation]*

The Canadian Medical Association is grateful for this opportunity to meet with the subcommittee. Since you will be hearing from other medical organizations and individuals involved with the issues you have identified to study, we will not attempt to cover all of these issues. We will focus on a few of them and will answer questions on the others to the best of our ability.

*[English]*

Some members of the subcommittee will recall our presentation of November 23, 1994. We stand by the recommendations we made at that time and will not repeat them today. Instead, we will focus on what has occurred since your report was issued in 1995.

In 1996, the General Council of the Canadian Medical Association approved a new version of the association's code of ethics that resulted from an extensive revision process lasting four years. Several articles of the revised code pertain specifically to the issues you are considering. For example, article 3 states:





Provide for appropriate care for your patient, including physical comfort and spiritual and psychosocial support even when cure is no longer possible.

Article 15 states:

Respect the right of a competent patient to accept or reject any medical care recommended.

Article 18 provides:

Ascertain wherever possible and recognize your patient's wishes about the initiation, continuation or cessation of life-sustaining treatment.

Article 19 states:

Respect the intentions of an incompetent patient as they were expressed (e.g., through an advance directive or proxy designation) before the patient became incompetent.

Article 21 states:

Be considerate of the patient's family and significant others and cooperate with them in the patient's interest.

Article 42 states:

Collaborate with other physicians and health professionals in the care of patients and the functioning and improvement of health services.

In 1998, the Canadian Medical Association updated the policy on physician-assisted death, which we presented to you in November 1994, and renamed it "Euthanasia and Assisted Suicide." The changes were relatively minor and were intended to bring the policy into conformity with the 1996 version of the code of ethics.

In our previous appearance before the committee, we discussed at length the joint statement on resuscitative interventions developed with the Canadian Healthcare Association, the Canadian Nurses Association, and the Catholic Health Association of Canada. A revised version of that document was published in 1995. Subsequently, the four organizations produced a pamphlet for patients, families, and health care providers entitled, "Making Decisions About Cardiopulmonary Resuscitation".

More recently, these same organizations developed a joint statement on preventing and resolving ethical conflicts involving health care providers and persons receiving care. Copies of all these documents are attached for your study.

These publications are evidence that the Canadian Medical Association has not been idle in regard to the issues addressed by this committee in your 1995 report.

Of the report's 28 recommendations, however, none was directed to our association. Many of them called for changes in the law or other initiatives by the federal or provincial and territorial governments. Since, for the most part, governments have not responded to these recommendations, there has been little opportunity for the Canadian Medical Association to participate in their implementation.

Although we agree with the spirit of most of the recommendations in your 1995 report, we respectfully





disagree with the call for Health Canada to develop guidelines and standards for the provision of treatment for the purpose of alleviating suffering where that may shorten life, for the practice of the total sedation of patients, and to govern the withholding and withdrawal of life-sustaining treatment.

Neither Health Canada, nor any other branch of government -- federal, provincial or territorial -- is capable of producing guidelines for medical practice. Some years ago, the Canadian Medical Association facilitated a guidelines development process that issued a set of Canadian clinical practice guidelines dated 1994. Guideline 7 of that document states:

Clinical practice guidelines should be developed by physicians in collaboration with representatives of those who will be affected by the specific intervention(s) in question, including relevant physician groups, patients and other health care providers as appropriate.

There may be a role for government in funding the development of such guidelines by the appropriate organizations, but governments should not try to do the development themselves. They have neither the appropriate expertise nor the requisite credibility in the area of clinical practice. We are asking for strong cooperation from government in helping national organizations develop these guidelines for the use of health care professionals in these areas.

On a more positive note, the Canadian Medical Association is strongly supportive of the efforts of organizations involved in palliative care to extend these services more widely. We have followed with interest the literature on the deficiencies of end-of-life care in the United States, especially the SUPPORT study, or "Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments". With financial support from the Robert Wood Johnson Foundation, the American Medical Association has developed a set of sophisticated curriculum packages for its "Education for Physicians on End-of-Life Care" program, which is intended to improve such care.

It is our understanding that the Joint Centre for Bioethics of the University of Toronto has received funding to extend this excellent program into Canada.

In 1998, Professor Donna Wilson and colleagues at the University of Alberta produced a voluminous report on "Social and Health Care Trends Influencing Palliative Care and the Location of Death in Twentieth-Century Canada." The Canadian Palliative Care Association has been revising its document "Palliative Care: Towards a Consensus in Standardized Principles of Practice." Health Canada is currently funding a project to produce "A Guide to End-of-Life Care for Elderly Persons", which should be finished within the next few months. The Centre for Bioethics of the Clinical Research Institute of Montreal continues to publish the internationally recognized Journal of Palliative Care. The Canadian Medical Association applauds these activities and looks forward to seeing their results integrated into mainstream medical education and clinical practice.

With regard to the issues of withholding and withdrawal of life-sustaining treatment, advance directives, assisted suicide and euthanasia, we consider that the Canadian Medical Association policies we presented to you in 1994 have stood the test of time and do not require revision. We stand by the recommendations we made to you when we appeared on November 23, 1994.

Thank you for this opportunity to speak with you. I look forward to your questions.

The Chairman: Thank you.

Ms Sharon Nield, Manager, Nursing Policy and Regulatory Support, Canadian Nurses Association:





Thank you for inviting the Canadian Nurses Association to participate in this important discussion. The CNA is a federation of 11 provincial and territorial nursing associations representing 110,000 registered nurses across the country. We welcome this update to your report "Of Life and Death" from a number of perspectives.

First, one of our key recommendations when we presented to the committee in October 1994 was to ensure broad public debate on end-of-life issues. This review provides the opportunity to further the discussions begun at that time and returns the issue to the public eye.

Second, we welcome the opportunity to reflect on and summarize our own activities in support of the committee's and our own recommendations. In keeping with the purpose of your task, we will restrict our remarks to our perceptions of the progress made, our own contributions, and recommendations for further emphasis.

We commend the committee for "Of Life and Death." The recommendations speak to many of the concerns we expressed, particularly those related to palliative care, pain control, advance directives, and education. Your comprehensive report reflects the very diverse views of your witnesses on this complex and difficult issue.

The landscape of the health care system has changed dramatically in the last five years. Some of these changes, such as increased multidisciplinary care, greater demand by consumers for information and for control over their own care, and advanced technologies for pain and symptom management have facilitated the adoption of the committee's recommendations. Other changes, such as shifts to community care without sufficient resources and a continued linking of end-of-life issues with resource allocation, have hampered the more comprehensive and appropriate policy framework that was envisioned and to which our colleague from the Canadian Healthcare Association has also referred.

End-of-life issues appear to have fallen from the public view, resurfacing only in light of high-profile media coverage in circumstances such as the Latimer case. This sparked much of the testimony at the time of the committee hearings. We continue to believe that public discussion and education, separated from individual circumstances that are very emotional, needs to occur. As our demographic profile shifts to an older population, these issues will increasingly demand a national policy approach to end-of-life issues.

The nursing profession, in conjunction with many of our colleagues around the table today, has played its part in implementing many of the recommendations contained in "Of Life and Death."

The CNA code of ethics for registered nurses, which establishes the ethical responsibilities for Canadian nurses, was updated and re-issued in 1997 following an extensive and lengthy national consultation process. Strengthening the ethical values of "choice" and "dignity" were key elements of the revisions. In guiding ethical decision-making, the code highlights the expectation that registered nurses will involve clients in decision-making, respect informed decisions of competent persons to refuse treatment, and will practice within relevant legislation governing consent or choice. It also highlights the need for nurses to respect decisions and lawful directives about care choices and to respect and honour clients' wishes regarding quality of life.

As well as providing the code of ethics, CNA has developed comprehensive educational material regarding application of the code for use by schools of nursing and provincial and territorial professional associations. We have also created a national ethics advisory committee to provide advice to CNA regarding further updates required to reflect the changing health care system and the need of nurses for





guidance within that system.

At the time of our presentation to the committee five years ago, we had just completed the joint statement, to which reference has been made this morning, with six other national health organizations, on advance directives. This has been widely distributed to nurses. In May 1998, we began a series of "Ethics in Practice" papers, of which the initial paper was on the nurse's role in advance directives. Again, this has been widely distributed to nurses and used by provincial and territorial nursing associations. It provides information about specific types of advance directives and case study examples.

The joint statement on preventing and resolving ethical conflicts has also been referred to by my colleagues. It was publicly released last June and has been widely shared with our members. Setting out the principles upon which informed choices can be made, the statement also provides health care organizations and professionals with specific guidance on a process to resolve ethical conflicts. This is a very important document, as we face increasingly difficult choices of care in a highly complex environment.

Beyond the leadership activities of professional associations, however, individual nurses have acted to clarify issues around end-of-life care and ethical dilemmas. One example was demonstrated by registered nurses in Montreal who experienced professional development sessions with a nurse ethicist. As a result, two of the staff nurses set about organizing an education project for all of the staff nurses within their unit that allowed them to develop end-of-life protocols and discussions on advance directives with every patient. Their project was presented to the Canadian Bioethics Society conference, later to the CNA biannual convention, and also to the International Congress of Nurses convention in London this past June. Key to their success was increasing the comfort level of the nursing staff, and all of the staff who worked with them, in handling the issue with patients. This is but one of many examples of how nurses are attempting to ensure that the choices of clients are supported and that ethical problems around end-of-life care are avoided.

In all, open discussion, respect for the wishes of the clients and their families, and clear institutional processes are key. Nurses believe that end-of-life issues must be considered in the context of the goals of care. If this goal-oriented approach is taken, we might reach a situation in which patients can find meaning in their decision-making because their choices are meaningful.

Despite the progress in terms of education, policy development, and care plans, however, we know there is more work to be done. The area of palliative care, which we highlighted in our 1994 brief, particularly home-based palliative care, remains of concern.

The funding cuts of the 1990s have resulted in an acute care system that sends people home "quicker and sicker," and little funding has been provided for community care. The committee's recommendation for an integrated approach to palliative care has not been realized. This has also been brought forward by my colleagues this morning.

Although those facing terminal illnesses may choose to die at home, supports are needed to ensure that they do so cared for, as free from pain as possible, and with dignity. People need to be free from the feeling that they are a burden. The burden of care should not rest on family members, who are also carrying the burden of loss and grief. It is often the lack of such supports, and the burden that is placed on their loved ones, rather than the illness itself, that make people consider assisted suicide.

We recommend that governments be encouraged to provide funding for quality palliative care programs in both hospital and home care settings. As noted by the committee, respite care is an essential





component of such a program.

We would encourage and support more research into palliative care, pain management, and quality-of-life issues, and hope that this will be a feature of the proposed Canadian Institutes for Health Research, once they are established.

We are interested in the comments of other witnesses regarding your recommendations on providing clarification with respect to the Criminal Code. While we have taken the approach that education, open dialogue, and sound policy direction should minimize the occurrence of litigation about end-of-life issues, we know that many of our members, particularly those who are working in home care settings, remain concerned about their liability.

In summary, we welcome this review and offer the following recommendations:

First, that the federal government continue to seek ways to enhance public discussion on the issues of euthanasia, assisted suicide, and end-of-life issues to truly determine what values we hold as a country, and that more public information be provided about consumer choice with respect to care and refusal of treatment;

Second, that research into palliative care and quality of life be encouraged through the auspices of the Canadian Institutes for Health Research;

Third, that a funded, integrated and national plan for community and home care be provided that will ensure quality palliative home care for Canadians; and

Fourth, that legislative changes be broadly communicated to the health care community.

Across the country, our nurses deal with difficult and complex issues of end-of-life treatment on a daily basis. The current state of the health care system has made it difficult for nurses to feel that they are meeting the quality of care and the ethical standards that they demand of themselves and that they are required by legislation to provide. The CNA will continue to provide a leadership role to assist and educate our members, and we look forward to your support.

The Chairman: I wish to thank all of you. We will now proceed to questions.

Senator Roche: First, I wish to thank the witnesses, who have been very informative.

I should like to ask Dr. Brazeau what he thinks of the following sentence: People are dying in excruciating pain; people are attempting suicide, failing, and ending up in worse shape than before they attempted suicide. That sentence is in the context of a plea for more palliative care facilities.

I can see I have given you a problem with that question. Let me rephrase it: Do you believe that people are dying in excruciating pain and that people are attempting suicide, failing, and ending up in worse shape than before they attempted suicide?

Dr. Brazeau: The answer to the first part of the question is that I am told that that has been occurring in Canada, that people are in excruciating pain and dying in that way. I am also told by the medical specialists who are caring for them with teams of other people that that is occurring less. What I am hearing mostly from these medical specialists is that we need to do much more to ensure that this no longer occurs.





Senator Roche: The chairman and the clerk will recognize that the sentence I read was from the brief of Professor Downie, who appeared before us, and who, in answer to my request to her, said that she would provide us with empirical evidence. Has anything arrived yet?

Dr. Heather Lank, Clerk of the Committee: Not yet.

Senator Roche: What happened this morning, with Senator Corbin's point of order and intervention, is illustrative of the problem that we are facing in this committee. When one of the witnesses went into the area of euthanasia and assisted suicide, from what I understood to be an advocacy position -- and I believe Senator Corbin also interpreted it that way -- it was brought to our attention that the mandate of this subcommittee is not to deal with those areas, but to deal with the unanimous decisions of the committee, which revolved around more palliative care. I sense that witnesses are coming before this committee -- not all, but some witnesses -- and are leading us toward addressing the areas that had divided the committee in its original report, assisted suicide and non-voluntary euthanasia. That leads me to wonder if we can, in fact, differentiate realistically. Does the public, even some of the informed public, consider palliative care to include assisted suicide and involuntary euthanasia?

Ms Nield, in her excellent testimony, concluded her remarks by saying that her association called for a greater discussion of questions around euthanasia to "determine what values we hold as a country."

I do not propose to try to resolve this dilemma at the moment. However, I am flagging it here to indicate my deep concern that our intention -- and the need for greater palliative care both at hospitals and at home in particular is obvious -- is perforce being clouded by the discussion that looms on the difficult questions on which there was not agreement. Personally, I do not know what to do about this.

The Chairman: Senator Roche, I am not sure this is the appropriate time for this discussion.

Senator Roche: It may not be, Madam Chairman.

The Chairman: I want to correct something on the record. When we heard the presentation this morning from the Canadian Pharmacists Association, you implied that their brief indicated that they would make some comments indicating their support of euthanasia. If you read the fourth point in their brief, senator, you will see that it is very clear. They have stated that their positions and recommendations, as stated in 1995, are still valid if the government were to legalize euthanasia. They certainly have not been advocates -- and they are not advocates now -- of euthanasia. That must be clearly on the record.

Senator Roche: Madam Chairman, I take your point. However, Professor Downie's previous testimony certainly led to a discussion, if not to advocacy, of this position.

Perhaps I will direct this question to Ms Nield. Nurses are on the front line of this whole subject. In your view, does the public differentiate between good palliative care on the one hand and assisted suicide on the other?

Ms Nield: I am not sure that I am able to speak on what the public believes. The experience of nurses is that there is a great deal of confusion around some end-of-life issues and on the nurses' responsibilities. I believe that quality palliative care is better understood now than it ever has been. I also believe that there are serious issues related to access to palliative care. I believe that alters the public's perception. It has not been my experience that palliative care and assisted suicide are intrinsically linked.

Dr. Crelinsten: I echo what has been said. I cannot speak for the public. I can speak for what I think the





members of the Canadian Medical Association feel, which is that participation in euthanasia and assisted suicide is not the job of members of the association.

Speaking as a physician who often cares for people near the end of life with severe, advanced cardiologic illness, my personal experience tells me that the patients I care for and in whose care I participate do not blur the lines between palliative care and the relief of suffering, whether it be physical, mental, spiritual or emotional, and assisted suicide. In fact, many of the patients who enter into that discussion feel that assisted suicide may be a failure of palliative medicine. They look to assisted suicide as a way out when the precepts and skills of palliative care physicians are either not available to them or are not sufficiently capable of dealing with the issues that they present.

Senator Roche: Ms Sholzberg-Gray, after receiving the report "Of Life and Death", which called unanimously for greater palliative care, and to which the government did not respond after witnesses told the committee that there is a crisis in palliative care, do you think the reason the government has not responded to the recommendations is that they did not want to get into issues that involve the highly controversial subject of assisted suicide and euthanasia?

Ms Sholzberg-Gray: No. The fact that the government -- and I am speaking here of the federal government, as well as provincial and territorial governments -- has not adequately funded health care, which includes all services, including palliative care, is not related to fear of discussing issues like assisted suicide but, rather, a lack of understanding or willingness to sufficiently fund the health care system in this country. Remember that some years ago -- in fact at the time that the committee first presented its report -- all governments in Canada were in a heavy cost-cutting mode. That was the objective of government at that time. We are now coming around to the notion that shifting the burden of the deficit to the health sector is not necessarily the way to go. It is not related to fear of discussing these issues but, rather, fear of spending money on those much-needed services. I am looking forward to the appropriate funding for those services, including palliative care.

The Chairman: Ms Sholzberg-Gray, do you also think that one of the causes may be that palliative care was kind of a new kid on the block at about the same time that these cuts were being made, and that because it was not part of the core funding, it has never become a part?

Ms Sholzberg-Gray: I think you are right. It is not the only thing that was the new kid on the block, so to speak. We are talking about a wide range of community services that are not properly funded and are not part of our core medicare services in this country, remembering that "medicare" is defined as hospital and physician services. We have not yet extended those services in the way that we should.

Some provinces have included palliative care as part of their core services in recent times. I understand, for instance, that your own Province of Manitoba, Madam Chair, is just bringing palliative care services into core funded services. That is an important move. The truth of the matter is that it would be useful if, when the federal government discusses with the provinces and the territories -- presumably as early as this May -- extending the continuum of care, that discussion could be broader than just home care or community care, and include a variety of services and mention by name palliative care and other kinds of services to which Canadians do not have access in any pre-determined way. It must be noted that we have this patchwork quilt across the country where, in one province, people might receive supplies and pharmaceuticals for palliative care at home, while in other provinces they do not. In some provinces, one might be able to die with dignity at home, while in other places that possibility is not there. The role of long-term care facilities in this mix, for example, is not well understood.

It is important to look at the health system in an integrated way, as the committee itself recommended.





and that palliative care services be understood and funded within that context. We are looking forward to the discussions that will ensue in May, now that we are looking to develop a health system that meets the needs of Canadians in all settings and for all kinds of services.

[*Translation*]

Senator Pépin: We heard last week the representations of palliative care associations. Following your representations, we all agree that the percentage of elderly people in the population has increased considerably and that more people get cancer and die of cancer. We are therefore unanimous in establishing that we should allocate more funds to the various associations and to research.

However, I would like to emphasize a point raised in the brief of the nurses association. You state in one of your recommendations on Chapter 8 that there is no need to modify the Criminal Code. The medical specialists said the same thing when they were consulted. Palliative care providers told us something must absolutely be done in that area. The nurses also mentioned in their presentation that the issue must be clarified. Can you tell me why your approach is different from the approach of the people on the front line?

Mr. Brazeau: The different point of view expressed by medical specialists is a reflection of the marked progress in the technology over the last five years. Such progress helped clear up the confusion which existed in the public and in the medical profession.

People involved in pain management and palliative care have benefited also from that evolution, and more information is available now. They feel more at ease to take medical and professional measures which might have a shock effect.

Nowadays, we talk a lot about the imputability of physicians. We would be quite willing today to advocate positions which would differ strongly from those we would have taken five years ago.

Such comments testify to the decision-making power physicians have acquired following a well defined clinical experience; a better understanding of the issues makes their task easier. This is why the Royal College of Physicians and Surgeons stresses education programs aimed at a better understanding of Canadian legislation, among other things, as one of the main solutions enabling us to go forward.

Senator Pépin: Is it one of the reasons why we should invest more funds in training programs?

Mr. Brazeau: We are now in an important period in Canada regarding the change in attitude on health services funding. Funding is not the issue. We must not lose sight of the need for a better integration of those services. People are working increasingly in teams or in cooperation with other people or other groups. Developing the models needed for a better integration of services is a complicated process. It is the main challenge for the years ahead. We have the ability to develop different management models, adapted to the regions, across the country. We will not be able to do it in one or two years, but the medical community is ready to take up the challenge. It is how the public should look at the renewal of health services.

Senator Pépin: We must simply keep learning how to work with the various levels.

Mr. Brazeau: We must dare to do it without forgetting the time it took to establish health services as we know them in Canada today.





[English]

Senator Pépin: I have a question for the representative from the Canadian Nurses Association.

You are the people who are working day-to-day with the legislation or recommendations. What are some of the elements of a quality palliative care system? What are patients' families experiencing today?

Ms Nield: The most significant element is access within an integrated and coordinated system. For example, nurses who work in community health centres in Ontario have told us that it is not possible for them to help their clients move into a palliative care program unless they have a particular qualifying diagnosis. The patient may not be dying actively enough to qualify for the particular program in their area. If a program is restricted or limited to someone who is very actively dying because there are fewer resources for that program, then it does not serve the broad, integrated approach that we ask for today. It needs to be integrated into that continuum of care, particularly with long-term care and the treatment of chronic illness. There must be a balance of appropriate treatment and pain and symptom management and control, as well as psychological, spiritual and emotional support for the individual within the context of the family.

What are people experiencing today? Some very fortunate people are experiencing that. The nurses who work within that system feel very fortunate to be there and to be able to provide care in that context. However, many people do not qualify, for whatever reason. Because of lack of access, because of the geography, because of the region, they are not able to access palliative care services. They may be dealing with end-of-life issues in an acute care hospital that does not have palliative care resources and is understaffed, underfunded, and overburdened. They may be dealing with it in their homes in which they have access to very little home care support. We hear from nurses who work in community and home care that it is a very difficult situation. I think that would be echoed by patients and their families.

Senator Pépin: Someone said that we must learn how to work together. I agree that it will vary from one region to another because we have different perceptions. However, you said that access is very difficult and you gave a reason. Is it also because of lack of money for the patient? Mr. Poston said that the cost of medication varies. He also said that, depending on the amount of money that they have, some can receive the best medication. Does it vary because the legislation varies from one province to another?

Mr. Poston: It varies because of the differences in drug plans across the provinces and also, obviously, depends on the patient's age and financial status. As a rule, a variety of those factors affect an individual's ability to qualify for drug benefit support.

Senator Pépin: Perhaps I misunderstood you, but did you not say that some families or people were removing patients from hospital?

Mr. Poston: We have heard of patients who, despite the codes of ethics in medicine, reported that advance directives were not being complied with.

In those situations in the hospital setting, the family had decided to care for the patient at home.

Senator Pépin: As a nurse, what are the main questions in dealing with the end-of-life issue?

Ms Nield: The lack of clarity about how well advance directives and the patient's wishes are really being balanced is a serious issue for nurses working in home and community settings.



I believe the individual ethical problems are being handled better. I believe there is more education, more understanding, more working together, but the increase in high-tech care, on the one hand -- the availability of very highly technological and acute care responses -- and the lack of resources for home and community care on the other, create an awkward situation to navigate.

Our nurse ethicists remind us that when we use the negative language of "withdrawing or withholding treatment", that often creates a situation in which the patients feel they will receive less of something. If we can move more toward establishing goals of care that respond to choice and the individual needs of patients, that will create a better context.

[*Translation*]

Senator Corbin: Dr Brazeau, I am trying to understand what is the specific role of the Royal College of Physicians and Surgeons of Canada vis-à-vis the general training of medical professionals. At the present time, in medical schools across the country, are physicians being trained adequately before they reach any level of specialisation? Is there adequate training in palliative care? Or is it rather a topic which is only dealt with very briefly? We were told five years ago that a few hours were dedicated to it before going on to more interesting topics.

Mr. Brazeau: I have to answer in the negative, it is not adequate. I have to tell you also that it is precisely the reason why measures have been taken to rectify the situation. Thus, there has been an integration of services. Regarding the medical profession, the first aspect of service integration we must look at is integration of medical services between specialists, family physicians and their colleagues.

We looked at the issue of palliative care together with the College of Family Physicians of Canada and we agreed on a one-year program of supplementary training in palliative care. It is certainly not sufficient, but it is a start.

Senator Corbin: It is however much more than what was done in the past.

Mr. Brazeau: Yes, and I actually gave you a list of medical schools which have such programs already and those having programs which will be certified soon. Nevertheless, the changes flowing from our standards and rules for each specialty regarding those issues are even more significant.

Another element might even be more significant: some people say that, in medicine, we are still paying the price of the industrial revolution and that we have fragmented the patient too much into medical specialties.

Therefore, the aim was to address such issues when, as early as in 1996, the Royal College looked at the general training as well as all aspects of training for medical specialists who must pay much more attention to those various roles, not only as specialised physicians but also as communicators. I see a direct link between their role as communicators and the challenges they will face with the integration of services.

It is not adequate, but we do not just stand idly by. Actions have been taken for years, the first results are obvious, and many more will be taken to ensure progress.

[*English*]

Senator Corbin: I would like to address a more general question and invite any of the interveners to





respond as they wish.

I thought I detected a desire -- it may or may not be subtle -- on the part of the organizations represented here this morning for a corporate view of codes of ethics development, and by that I mean, to a certain degree, to the exclusion of government or governments.

In other words, what you are saying is, "We, of all the people in this country, are best placed to develop significant, up-to-date codes of ethics and practices in the alleviation of human pain. Yes, the government may provide us with the funds, of course." I subscribe to that last part. There are underfunded initiatives that require more attention. I come back to what I call your "corporate view". To some extent, I believe in that myself. It is you the practitioners, with the education, the formation, the experience, the knowledge, and the cross-pollination in day-to-day practice, who are most capable, if you wish to put your mind to it, of developing a broadly based code of ethics and practices that aim at alleviating human pain and making the passage to death more supportable.

I wonder if you understand my point.

Dr. Henry Dinsdale, Past President, National Council on Ethics in Human Research, Royal College of Physicians and Surgeons of Canada: Madam Chairman, if I might respond to that, this is an extremely important issue. I might use a comparison with the United Kingdom, where in 1973, the Department of Health asked the Royal College of Physicians in London to come up with ethical review guidelines on the use of humans in research. There was a clear interaction and request from government. The Royal College of Physicians responded by putting together a set of guidelines that the United Kingdom Department of Health adopted two years later.

I think one of the problems we have in Canada is a marked under-utilization by government of the enormous strength and wisdom of the professionals in the country. It is a very muddled situation. I think Dr. Crelinsten referred to this in part.

We see it, for instance, in the Health Protection Branch and aspects of regulation of drugs, where there is already a very close interaction between government regulators and industry, but where there is a steep learning curve required on interaction with the professionals who are willing and able to provide advice.

I see this as one of the real challenges of the health care system.

In an odd way, in a federal system, you are able to promulgate national standards primarily through either non-governmental or relatively free-standing organizations.

For example, at the Royal College we can set national standards for the training and practice of specialists, although obviously each province has its own licensing authority. That is also the case with the hospital associations. In an odd way, these groups that are at somewhat of a remove and have strong moral suasion are able to have standards established, enforced, and accredited across the country.

A question was asked about the lack of response from Health Canada to some of the previous suggestions about guidelines. I would have been interested to know how Health Canada either maintained a silence on that or responded to it. It is only within the last few months that Health Canada has begun to put together an envelope of ethics. It is now beginning to think about this situation and ask: What should the role of Health Canada be in looking at some of these issues? I have no idea what answers they will come up with, but I think they are beginning to ask the questions for the first time.





Dr. Brazeau mentioned that I am past president of the National Council on Ethics in Human Research, a group that has been supported by the Royal College, the three funding research councils, and Health Canada. An important question now is: How will we evaluate the research ethics boards across the country? The kind of mechanisms we need are the ones for which we find models at the Royal College. A clear question should go out to these professional organizations, and government can do what it wishes with the response. We must better develop that interaction.

Ms Sholzberg-Gray: I think Dr. Crelinsten was talking about the importance of developing clinical guidelines and the role of the Canadian Medical Association in that area. I think that is an important role. Having said that, though, it is important for Health Canada to play some kind of brokerage role through the federal, provincial and territorial committees that meet on a regular basis. Again, that points to the complexity of our country, where we have a federal system and a shared responsibility in health. Some would argue that the federal government sets national standards and uses spending power. However, some provinces would dispute that statement and say that delivery of the system is in the hands of the provincial governments. Somehow -- that is, through the federal, provincial, territorial committee process -- more work must be done. In addition, the federal government could help through funding processes, including bringing together a number of stakeholders such as national associations, which do not hold all wisdom, understanding that the public interest must be represented in any cooperative mechanism.

Those are ways in which the federal government could bring people together without being prescriptive. We were all saying that they should not to lay down the guidelines and impose them on anyone. I think it is a complex issue and we all have a role to play here, including all the governments and the public.

Mr. Poston: You said the professions can play a key role in the development of ethics and guidelines. However, is there a need for research to inform that process and for information to be systematically gathered and analyzed to help formulate such guidelines and ethical statements? Building on what Ms Sholzberg-Gray said, there is a real need for public consultation so that we have a clear understanding of what the underlying societal values are on which we will base these ethics. That is particularly important, given the multicultural nature of Canada.

As the Chair pointed out, our comments with respect to the Oregon experience are solely based on the fact that we made some conditional statements in our 1995 brief, wherein we stipulated, "if the government was to do things." We were drawing the committee's attention to some research and to an experience that has addressed some of the conditions that we had mentioned with respect to "if that was the case." It is learning from experiences in other areas, which is part of the research process, that will help us inform the development of such guidelines and the formulation of appropriate ethics.

Senator Beaudoin: I would like to come back to the basic question of the Criminal Code. I am very surprised to hear that, today, there is less need to modify the Criminal Code than in 1995.

It is difficult to amend the Criminal Code, although we do it regularly from time to time. In this field, however, it is much more difficult. Is the public aware of the differences between withdrawing and withholding, and so on? My answer is "No, they are not aware."

I remember a discussion I had with some experts on this matter. In 1995, we were able to develop a lexicon: What is euthanasia? What is assisted suicide? Thank God, we succeeded. It is very positive, in my opinion. However, it does not mean that everyone agrees with that lexicon. That is the problem. We were unanimous in many fields but we were majority/minority-minded in two areas. Finally, we will draft a bill on the subjects where we were unanimous. We should have had them that much earlier, but



we did not succeed.

There are two ways to settle this problem: Leave it to the courts or do our job. Our job here is to develop better laws. There is no doubt in my mind that we have a lot to do. The provinces have a lot of competency in that field. In the area of the Criminal Code, we are king; in the area of health and welfare, we are not. We are very important, but we are not alone.

[*Translation*]

Dr. Brazeau, why do you say that there is no need to amend the Criminal Code?

Mr. Brazeau: We do not say that it is not necessary to modify the Criminal Code. We say that, from the point of view of specialized medicine, it is not necessary to change it. Our medical specialists tell us that, with the experiences of the last few years, a better understanding of the Criminal code contents, of what it means and how it is to be applied on a day-to-day basis, has answered their concerns and eliminated the existing barriers to providing specialized care in Canada. Nevertheless, we are not saying that it might not be necessary for other reasons.

[*English*]

Senator Beaudoin: I agree with you entirely.

The Chairman: Senator Beaudoin, I have a supplementary question. When the representative of the family physicians was here last week, he indicated that, because of the Dr. Nancy Morrison case in Nova Scotia, there was a real chill on providing adequate amounts of opiates -- not potassium chloride, that was a whole other issue. Doctors were now retreating from giving adequate amounts of pain relief. How would you respond to that?

Dr. Brazeau: That was specifically alluded to with the medical specialists with whom we have been discussing this issue. In fact, they did not express the same point of view as was put forward by the family physicians. They claim that they see things differently. I indicated earlier to Senator P  pin that the members commenting now are saying that, in their own units, they are seeing clarification of the interpretation of the law and how it should be applied, and clarification of what it is possible for them to do.

They are feeling a greater empowerment and are willing to move forward, to do the analysis necessary to make the required decisions, and to take the necessary action and ultimately be willing to defend their actions and be accountable for them.

Senator Beaudoin: I would agree with you in the case of palliative care. There is no problem there, in my opinion. There is a question of money and some other issues, but palliative care is not a big problem. We are all in favour of it. The provinces have a lot to do, since hospitalization is provincial. Do not forget that.

We, the federal authority of this country, also have a lot to do in health. We have jurisprudence in the field of withdrawing and withholding treatment. In my opinion, that is not good enough. It should be clearer, and the only way to render that clearer is to amend the Criminal Code so that the doctors and the nurses will be protected. They will know, at last, what they can and cannot do. That is not bad thing, in my opinion.





Dr. Brazeau: I repeat that our intention is not to prevent you from doing this. I do suspect that, from the discussions with the specialists that we have been relating, some other thoughts come to mind. It is quite clear that the specialists we have talked to are convinced that moving ahead and getting substantial progress in terms of palliative care would impact on the other issues that are before us, including the withholding and withdrawal of services, and would probably attenuate considerably some of the other issues confronting them or that have confronted them in the past.

The underlying concern is that if there are modifications to the Criminal Code, as put forward by a number of our people, we must then go through the process of interpretation of the new rules. At this time, they are concerned about the major impacts that a change in the Criminal Code could bring about. They do not necessarily see that impact as essentially and fundamentally positive.

Dr. Crelinsten: In our presentation this morning, we did say that the Canadian Medical Association stood by the recommendations we made on November 23, 1994. For the record, it is important to reiterate the recommendation on this particular issue. We do agree with Senator Beaudoin that it is important that the general part of the Criminal Code be clarified so that physicians are not culpable if they withhold or withdraw treatment that patients do not want. We made that recommendation in 1994, and I think the Canadian Medical Association would stand by that.

Ms Sholzberg-Gray: I am a little reluctant to speak about the law. I must admit that, once upon a time, I was a practising lawyer. I no longer am. I understand Senator Beaudoin's concern about relying on the jurisprudence, since that jurisprudence may not always be clear and give direction to people in the field -- doctors, nurses, and others, including hospitals that belong to my national association.

The joint statement, to which we referred, on resolving ethical conflicts is one step in the right direction. Underlying that joint statement is a clarification and understanding of what withholding and withdrawing treatment means and the necessity for proper communication between families and people providing care. Hopefully, it will mean that hospitals and professionals will not be subject to prosecution or litigation. It does seem that things would be clearer if these items were clarified in the criminal law, which is the one area in which the federal government has absolute jurisdiction.

However, one reason people put forward for not doing it is that these kinds of joint statements have meant that, in practice, people seem to be working quite well in explaining withholding and withdrawal of treatment, so the criminal law might not be needed. Then again, it might be needed for further clarification.

Senator Beaudoin: This is an interesting point because it comes from the experts, and I believe in experts. Another point is the guidelines. You say that the House of Lords in the United Kingdom has engaged in some consultations in order to learn more about the guidelines. I think they are right and we should do that in this country. However, our problem is a bit more complicated. Sometimes we need guidelines in legislation, especially with the Charter of Rights and Freedoms. We have a tremendous amount of jurisprudence -- 400 cases -- on the Charter of Rights and Freedoms. You need to be quite an expert to understand it all. It applies to everyone, and our world is becoming more and more complex.

I agree that we, the legislative branch, should not draft or make guidelines without consulting the doctors, the nurses, the hospitals, et cetera, because they know what we do not. However, we must do our job. Sometimes guidelines need to be crafted by Parliament or the Governor in Council, after consultation with the authorities concerned, in order that the population knows exactly what can and cannot be done.





If you give that power to certain groups, as brilliant as they may be, the results could vary from one province to another. We need some standards in this country on health care. When something is contained in the Criminal Code, there is no problem because it applies across the country. That is quite an asset. Those who do not have that arrangement look at Canada and say, "Oh, you were right." In that sense, although we should have a great deal of consultation, we must accept that, in the end, the guidelines should be contained in our laws and regulations. Do you want to leave that to the doctors and the associations, with the risk that it may vary from one province to another? That worries me.

Dr. Brazeau: We agree that we should have national standards and we are a national standard-setting organization. Within the realm where we intervene, we see our role as being very effective. Internationally, in much the same way you pointed out previously, it is perceived as a marked strength for Canada to have a standard-setting association of this type.

More specifically, on the issue of how that clarification could be brought about, I am not prescribing anything, but I am indicating that our members are not seeing a need for this at this time. It might be necessary for other groups in society. It is also important that we dissociate the issues that we have related in terms of ethical and other practice guidelines. Our own organizations are becoming much more aware of the necessity of getting the public involved in all that we do. Our activities are now conducted with the participation of lay members on our boards, our groups, and our committees, and they are contributing very strongly. This is certainly helping us along.

I do not have a final comment on which way we should go in terms of the Criminal Code. I have only brought forward our own opinion on this.

Dr. Crelinsten: This is not an easy situation to address. Much of what has to be clarified probably has more to do with the actual meaning of words than the operational organization of guidelines.

I was referring to the kind of guidelines that health care professionals use as clinical practice guidelines. They allow health care professionals, on the basis of evidence, to proceed in a way that is more likely to produce good results than bad ones.

These kind of guidelines, whether they are concerned with treating acute myocardial infarction, end-of-life issues, or complex cancers, are best established by the professionals who work in that area.

There is no doubt that Health Canada, as an arm of government, has a responsibility to facilitate those professional groups that should be required to prepare those guidelines and actually do the work, whether it be in spirit or financially. It may even be that they can facilitate the appropriate experts that the professional societies may require to improve their guidelines. However, the ultimate responsibility for the knowledge, skills and attitudes that are required to carry out those clinical practice guidelines that result in interactions between health care professionals and patients ought to reside with the professionals who are expected to operate by those guidelines.

I may now be speaking personally rather than as someone from an organization. The ultimate role for lawmakers and government is to establish for the professional organizations in this country a moral compass by which you measure the values of society, and we then operationalize them for you.

When we hear your values, we have difficulty operationalizing them, primarily because of issues which revolve around funding, human resources, and knowledge. That is what I meant with respect to guidelines being established by professional organizations, which also have a responsibility for self-governance and self-regulation and to ensure that they do the best thing, albeit with the strong input



of the moral compass and the organizational structure that organizations such as Health Canada can provide.

Mr. Poston: My colleague from the CMA has eloquently pointed out that it is the role of the professions to develop the guidelines that will be used in the decision making of individual practitioners in the care of patients. However, Health Canada, along with the provinces, has an absolutely critical role in providing the structure, finance, and administration with respect to the health care system. In that way, the environment within which practitioners have to make those decisions and provide that care will be supportive and adequate to meet their needs.

One example of that is Health Canada's recent initiative with respect to the development of home care. It is a very good example, although it is an extremely difficult task. Home care is variable, fragmented, and financed through different mechanisms. However, it is an initiative in which Health Canada has a critical role to play in terms of facilitating and developing the process. Thus, we will be able to achieve greater harmonization with respect to the accessibility, the nature of services, and the funding that is available. As a result, individual practitioners will have an environment in which they can provide the standard of care that our patients deserve.

Senator Beaudoin: It is within the framework of the country, which is a federation. We have to fall within the Constitution and the division of powers. However, there are many ways in which there may be cooperation between Ottawa and the provinces. We are experts in that field. There is also the question of money and the famous spending power. If we have too much money, we may spend it for good reasons. I think health is one of those.

[*Translation*]

Senator P  pin: My approach is somewhat different and is based on my experience in the field. When I was a nurse and our medical specialists came, we had to apply the regulations. Clearly, they were the bosses in the department.

We told them often: "What you say is true, but when it comes time to apply the regulations, we should simplify some things, improve some practices. It would make it easier and we would have far less problems.". We are faced with the day-to-day activities of nurses who apply the palliative care regulations and we are faced with the experts who give us their advice.

I believe it will be very interesting to communicate again with you.

[*English*]

The Chairman: Ms Nield, you indicated that patients are being released back into the community "quicker and sicker", I think was your expression. I think we have all accepted that. My own experience is that they are released into the community, however, without much in the way of directives, without much in the way of support, and without much in the way of funding.

In your experience, what do you think is needed to make quality palliative care, which I think is available in many of our senior hospitals, available through a home care delivery system?

Ms Nield: What is needed is an integrated system in which the same kinds of services that are available in hospitals are available to someone in a home and community setting. That would include access to appropriate professionals, funding for drugs and treatments, and access to support both for the individual





patient and the family members who are caring for that patient.

We hear today that home and community care is often off-loaded onto individual family members. I have with me a research report released by the Status of Women that indicates that there is a significant amount of off-loading for home care onto females. They, in turn, suffer in a variety of ways, including career development, health problems, and poverty.

In nursing, one of the issues that we have struggled with in the last decade is that the amount of professional development and education funding for nurses who generally work as employees has been cut dramatically. It is very difficult for nurses to increase their skills in palliative care and in home care.

The Canadian Palliative Care Association has a nursing committee that has asked us to develop a certification program for palliative care nursing as a specialty. Currently, there is no funding for that. The resolution of that issue would move this forward.

The Chairman: Mr. Poston, when you were presenting your information, I was concerned that you seemed to be indicating that your association does not believe that there is sufficient opiate treatment being made available to many patients in this country.

Mr. Poston: Since 1995, we have seen an improvement in the use of medications in palliative care. What is being reported to us -- and I think the evidence you received from the College of Family Physicians would echo that -- is that there is still a reluctance to provide adequate dosage by some physicians. That points to the need for ongoing training and education in the area.

The Chairman: In your experience, would that more likely happen in a home care setting than in a hospital setting?

Mr. Poston: It is more likely to happen in a home care or community setting, where physicians may not have received training. It really points to the need for education and training in that area, yes.

The Chairman: I think the profession has come to a realization that doctors' time is valuable time as well.

I congratulate doctors for finally deciding that they deserve some quality care time in their lives as well. Nobody can be a 24-hour physician, any more than you can be a 24-hour anything.

That leads us, it seems to me, into an increasing dilemma in our communities. If we are going to have more and more care delivered in the community, how are we going to restructure the time of physicians so that they will then be willing or able to deliver that service in the community, when most of their structure is built on the doctor's office and the clinical setting? I would suggest it is rarely, any longer, in the person's home. How are we going to change that dynamic?

Dr. Brazeau: The medical profession has already indicated that it is willing to take up that challenge. The references to the necessity for better integration of services, and to look at it in terms of the continuum of care, are important. In fact, the medical community comes together in a setting which is supported by the Canadian Medical Association, which is called the Canadian Medical Forum. That forum has looked at the issue of the current shortage of physicians in some specialities, but it is focusing even more on the need, at this time, to start thinking "out of the box" and to stop looking at issues in the same terms as in the past, as far as health care service organizations are concerned. We are starting to talk about needs.

It will not surprise anyone that in fact we have not, in terms of physician supply, looked at needs at any





time in the past. We have been managing supply, essentially, and trying to use some surrogates in order to define need. We now must approach the issue of need more effectively. Fortunately, it appears that the methodologies to do that are now becoming available. In the past, they were not. We now need to focus, in the medical community and beyond, on how we can best work together, how we can best integrate the services, and how we can best provide the continuum of care. This will probably mean a different sharing of responsibility.

Physicians in our community have already sought our help in order to ensure that, in rural settings, for example, it becomes possible for physicians to acquire advanced skills, special skills, and to provide better care. This will require collaboration on the part of specialists. The Royal College is already on record that we will collaborate with the family physicians to accomplish that. That sets an example. The type of integration that we can perhaps accomplish within the medical community, which will go through further education and training, which will go through different sharings of responsibilities, is something that we can start looking at and modifying in terms of the relationships between different health care professionals. We are willing to do so, and we have started to take up that challenge. The medical community is doing it at the Canadian Medical Forum, which brings together all our different organizations.

Dr. Dinsdale: Part of what you raise is really the use of the physician's time. Here, in addition to interaction with other health care professionals, it is important for physicians to understand that the activities they undertake each day can be broken down into four different groups. There is the core diagnostic and treatment role, which they must play. There is a pastoral role, which sometimes gets confused in different aspects. There is a very heavy administrative burden put on many specialists in hospitals. We also expect many of these people to be doing research. These are four important areas, and physicians have to get it clear in their own minds which roles they feel are essential ones in an area where there is a great shortage of workers in the professional field. Interaction with other groups is extremely important, and obviously interaction with the nursing profession and social workers is key. People need to be clear as to what their role is.

Having said all that, it is my clear belief that, although we hear a lot about community care, community care really is care by the community. This is the great burden we are hearing about on women in our society as a result. I think we have to realize that this is a realistic result of the off-loading of care into the community. There just will not be enough health care professionals to deal with this, and in that sense, you need to look at some sort of relief, particularly for women in our community who are coping with this. There is a real domino effect in this process.

Ms Sholzberg-Gray: I know you directed your question to doctors, and of course they play an important role in providing all kinds of care, including end-of-life care, but we are talking about care in the community. We are not only talking about doctors, nurses, and social workers, but all the community supports that enable people to live in the community. That includes homemaker services and home-support services, which have not been alluded to up to now, and which could help families, particularly women, in their efforts to take care of people who are dying in their homes. We have to look at the multiplicity of services -- not just the professional ones, but the ancillary services that enable people to live in communities. We ought not to forget that. That is part of providing care across a broad continuum.

Senator Corbin: Mr. Poston made a statement that I find disturbing or unsettling. He said that, in some provinces, patients have been admitted to hospital in order to receive their medications free of charge. He also said that, when one considers that patients live longer and that their quality of life is greatly



enhanced by spending their final days in their home environment, forcing them to be in hospital because medications are paid for seems counterproductive and somewhat inhuman.

How generalized is that practice and who is responsible for forcing patients into hospital?

Mr. Poston: I would say it is a fairly common feature of the Canadian health care system. Because drugs are not part of the Canada Health Act, patients end up being kept in hospital in order to get expensive drug treatment.

Senator Corbin: Because they are too poor or because their families do not want to pay?

Mr. Poston: Because drugs are not part of the Canada Health Act, they are not covered. The only coverage that you have for drugs in the Canadian health care system is provided through provincial drug benefit plans or through private insurance. This affects people who are not eligible for a provincial drug benefit plan. They may be unemployed, but this particularly affects the working poor because, while they may be employed, they may not qualify for drug plans provided to people receiving welfare or social assistance, and yet still may not be able to afford treatment. In some of the provinces, the deductible for drug treatment is as much as \$1,700 before the provincial plan kicks in. It is a real problem.

Senator Corbin: Then you are compounding the problem of too many patients and waiting lists in hospitals for people who need important and direct medical intervention.

Mr. Poston: A very important part of the federal initiative around home care is to look at providing one of the things we strongly advocated for as an association, which is the provision of a pharmaceutical benefit as a part of whatever turns out to be the national home care initiative. If that were available, the decision to discharge a patient from hospital would not place the patient at risk of not having the drug therapy that they have perhaps been stabilized on in hospital. A very important plank of the development of home care and community care is to ensure that people have access to the appropriate medications.

Dr. Dinsdale spoke of the administrative burden that physicians face. A major administrative burden for pharmacists in the community, and for family physicians, is just sorting out access to medications. We have done a study that shows that as many as 70 per cent of new prescriptions written in Canada require additional administrative workload by the pharmacist, and often by the family physician, to determine what coverage that patient has. Our president was working in his pharmacy last week, and he had to transmit a drug claim six times for six different drugs. He was trying to find an antibiotic that was covered by a patient's drug plan, and with the physician waiting on the phone, he transmitted six claims on line before he found one antibiotic that the patient's plan was able to cover. That is a good example of the significant burden that community pharmacists and family physicians are facing in trying to deal with improving access to medications.

Senator P  pin: I have a question of clarification. Mr. Poston, you mentioned that caregivers should be free to refuse to give a specific treatment, but do you not think that then they should refer the patient to other doctors or to a palliative care centre?

Mr. Poston: Yes. Our code of ethics, and our recent national statement on refusal for care, have a requirement that that patient be referred to somewhere where they can gain access to that service or that product.

The Chairman: I thank you all very much. This has been a very informative session.





The committee adjourned.









Français

# Proceedings of the Subcommittee to Update "Of Life and Death"

## Issue 4 - Minutes of Proceedings

OTTAWA, Monday, February 28, 2000

(6)

[English]

The subcommittee to update "Of Life and Death" met this day in room 257, East Block, at 1:03 p.m., the Honourable Sharon Carstairs, Chair, presiding.

*Members of the subcommittee present:* The Honourable Senators Beaudoin, Carstairs, Corbin and Pépin (4).

*Other senator present:* The Honourable Senator Roche (1).

*In attendance:* Mollie Dunsmuir and Nancy Miller-Chénier, Research Officers, Research Branch, Library of Parliament.

*Also present:* The official reporters of the Senate.

*WITNESSES:*

*From the Department of Health Canada:*

Barbara Ouellet, Director of Home Care and Pharmaceuticals, Health Care Directorate, Policy and Consultation Branch;

Nancy Garrard, Director, Division of Aging and Seniors, Health Promotion and Programs Branch;

Dr. Christina Mills, Director, Cancer Bureau, Laboratory Centre for Disease Control, Health Protection Branch;

Leslie Gaudette, Section Head, Treatment and Palliation Section, Cancer Control Assessment and Surveillance Division, Cancer Bureau, Laboratory Centre for Disease Control;

Debra Gillis, Director, Health Programs Support Division, Medical Services Branch;

Cliff Halliwell, Director General, Applied Research and Analysis Directorate, Information, Analysis and Connectivity Branch.



*From the Elisabeth-Bruyère Health Centre:*

Ms Maryse Bouvette, nurse, Palliative Care Program;

Dr. Cori Schroder, Palliative Care Program;

Dr. Ray Viola, Palliative Care Program;

Diane Hupé, Vice-President, Palliative Care Program.

*From the University of Toronto:*

Dr. Peter Singer.

*From the University of Manitoba:*

Dr. Harvey Max Chochinov, Department of Psychiatry.

The Chair made an opening statement.

Barbara Ouellet, Nancy Garrard, Dr. Christina Mills, Debra Gillis and Cliff Halliwell each made a statement and, together with Leslie Gaudette, answered questions.

Pursuant to its Order of Reference adopted in the Standing Senate Committee on Social Affairs, Science and Technology on Monday, November 29, 1999, the subcommittee continued its examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death". (*For full text of Order of Reference, please refer to Issue No. 1*)

At 2:40 p.m., the subcommittee suspended.

At 2:46 p.m., the subcommittee resumed.

The Chair made a statement.

Maryse Bouvette, Dr. Cori Schroder, Dr. Ray Viola and Diane Hupé each made a statement and answered questions.

At 4:05 p.m., the subcommittee suspended.

At 4:18 p.m., the subcommittee resumed.

Dr. Harvey Chochinov made a statement and gave a slide presentation.

Peter Singer made a statement.

The witnesses answered questions.

At 5:29 p.m., the subcommittee proceeded to consideration of a draft budget.

It was moved by the Honourable Senator Beaudoin -- That the following budget be submitted to the Standing Senate Committee on Social Affairs, Science and Technology for approval and submission





to Internal Economy, Budgets and Administration:

Professional and Other Services	\$1,350
Transportation and Communications	5,290
Other Expenditures	1,250
Total	\$7,890

After debate, it was agreed.

At 5:37 p.m., the subcommittee adjourned to the call of the Chair.

*ATTEST:*

Heather Lank

*Clerk of the Subcommittee*







Français

# Proceedings of the Subcommittee to Update "Of Life and Death"

## Issue 4 - Evidence

OTTAWA, Monday, February 28, 2000

The Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 1:03 p.m. to examine the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled, "Of Life and Death".

Senator Sharon Carstairs (*Chairman*) in the Chair.

[*English*]

The Chairman: Good afternoon, everyone. Today is our fourth hearing under our mandate to update the unanimous recommendations of the 1995 Special Senate Committee report on euthanasia and assisted suicide entitled "Of Life and Death." I would remind everyone -- honourable senators, witnesses, and those watching on television -- that this committee is not reopening its debate on assisted suicide and euthanasia; it is dealing strictly with the areas of the report where the original committee made unanimous recommendations. I would ask that everyone bear that in mind as we proceed with the hearings.

Before us today are three panels of witnesses who have been invited to address us on the issues that were raised in the report for which there were unanimous conclusions. First, we have the officials from Health Canada. Later this afternoon we will hear from representatives of the Elisabeth Bruyère Health Centre. Our third panel will consist of Professor Peter Singer from the University of Toronto and Professor Harvey Chochinov from the Department of Psychiatry, University of Manitoba.

We will begin with the witnesses from the Department of Health and Ms Barbara Ouellet, Director of Home Care and Pharmaceuticals. We would ask all the witnesses to be as short and as succinct as they possibly can because the senators gathered will want to ask them many questions.

Please proceed.

Ms Barbara Ouellet, Director of Home Care and Pharmaceuticals, Health Care Directorate, Policy and Consultation Branch, Department of Health Canada: We have relatively brief remarks to make to you today. We will make our remarks first and then collectively entertain your questions. My remarks today will focus on the work we are doing in the area of home and community care, which includes palliative care as one of the aspects of treatment of clients in that area.



It is a pleasure for me to be here today to update you on our work and to speak a bit about how our work relates to the Senate report "Of Life and Death" that was tabled in June of 1995. Following the tabling of the report, Health Canada established an inter-branch committee to review the recommendations and to assess how action in these areas might be incorporated into the work of the department. In fact, we have discovered that the completed and ongoing work of the department touches directly or indirectly on many of the committee's recommendations relating to palliative care. I and my colleagues here today will be updating you on some of these initiatives. I would also mention that we have already begun to prepare a summary of the relevant work that we have been doing to date. Once this work is completed, I would be happy to provide that to the committee members for your information.

One of the key recommendations of the Senate report was that governments make palliative care a top priority in the restructuring of the health care system. In September of 1998, all health ministers identified continuing care, which encompasses home and community care and institutionlized long-term care, as one of their key priorities for collaborative action. In September, 1999, health ministers reviewed progress to date and reaffirmed their commitment to these priorities.

In follow up, officials within the department have been working with our counterparts in provincial and territorial health ministries to assess the major pressures and changes facing home and community care, and to identify possible directions and priorities for enhancing services in this sector. In addition, our focus is on how to strengthen the coordination and linkages within other sectors of the health system and between these sectors -- for example, between home and community care and primary, acute and long-term care -- in order to ensure that Canadians have more seamless access to an integrated array of services based on their health needs.

In particular, we are in the process of preparing a detailed overview of current home and community care programs, including the range of available services, client entitlements and current budgets. We have also begun to consider possible common objectives that all jurisdictions could agree on and which would set a realistic but progressive vision for strengthening home and community care over the near and longer term.

Palliative care is one of the types of client needs that is usually addressed through home and community care programs. In this sense, then, our focus is on integration within and across the sectors of the system and, in doing so, will be consistent with the recommendations of the Senate report that spoke of this need in regard to palliative care.

One of the other recommendations of the report concerned promoting and supporting research into palliative care. The subcommittee may be interested to know that home care is one of four priorities under the Health Transition Fund. This fund was announced in the 1997 budget and totals \$150 million over about three to four years. In addition to home care, other priorities of the fund include primary care, pharmaceuticals, and integrated service delivery.

A number of projects in the areas of home care and integrated service delivery focus on palliative care. For example, one project which is supported by both the Nova Scotia and Prince Edward Island Ministries of Health is a demonstration project on rural palliative care. We have a project in Quebec which is supported by one of the CLSCs that is looking at the development of an information and training guide on home care and services for persons with cancer. Another CLSC is leading a project looking at the development of a continuum of care and services for ill adults. Finally, a project in Saskatchewan is reviewing and evaluating the current palliative care program in one of its health districts.





In summary, then, as I believe I have indicated, there is already quite a bit of work that is underway and that will be continuing with respect to palliative care. In view of the agreement among FPT ministers to give priority attention to home and community care, this will be an area of ongoing collaborative work aimed at strengthening the availability and integration of such services, including those related to palliative care.

Ms Nancy Garrard, Director, Division of Aging and Seniors, Health Promotion and Programs Branch, Department of Health Canada: I am also pleased to be with you today to discuss this important issue.

The role of the branch on this issue is varied and includes support for community-based initiatives, public and professional education, knowledge development and dissemination, as well as collaboration between governments and agencies on various shared projects. The branch focuses on addressing health issues across the lifespan using a population health approach.

By using this approach, Health Canada recognizes the importance of end-of-life issues across the entire spectrum of life stages: childhood and youth, mid-life and later life. We certainly see a particular need for attention for end-of-life care issues for Canadian seniors. As you probably know, over 75 per cent of all deaths in Canada occur in people over the age of 65. Certainly, with the aging of Canada's baby boom generation in the coming decades, end-of-life care issues, including palliative care, will become even more prominent.

Under the "Promotion of Population Health" business line adopted in 1997 by our department, addressing end-of-life issues is noted as one of the four priority themes for the later life population. This priority has continued over the past three years and was selected partly as a result of the findings and recommendations of the Special Senate Committee report, "Of Life and Death."

The majority of our work has been in supporting innovative community projects to raise awareness of end-of-life concerns amongst the health community and other stakeholders. We have also supported the development of public education materials, knowledge dissemination activities and support for national health voluntary organizations working in this field. In total, we have contributed over \$2.9 million over the past five years to these initiatives. In particular, we have funded 10 major community initiatives pertaining directly to end-of-life issues for seniors as well as six major projects pertaining to the care of HIV/AIDS patients. These particular projects have been consistent with many of the recommendations made by the Special Senate Committee.

One example is the development of a manual of national guidelines to support the end-of-life care of seniors. This project is sponsored by the Sunnybrook Health Science Centre at the University of Toronto. The guidelines, which are consistent with the recommendation of the development and implementation of national guidelines, are scheduled to be released this spring.

Another example is the support we provide to an international symposium on care of the dying. This is a project sponsored by the Sisters of Charity of Ottawa Health Services. The symposium will take place in April, 2000. This is consistent with your recommendation that research into palliative care be expanded and improved and disseminated to those who need this information.

We have also developed a 17-module national palliative care training package for health support workers and the implementation of a national network of educators to deliver this training program. The multiyear project will be in conjunction with the Canadian Palliative Care Association as well as the Canadian Association for Continuing Care. This is consistent with your recommendation that the training of health care professionals, in all aspects of palliative care, be increased. To date, this package





has been well received and used by the health care community.

The branch has also facilitated the dissemination of information to the general public through the publication of a palliative care information sheet for seniors. I have made a copy of this available to the clerk. This was a joint project with the provinces and territories under the auspices of the federal, provincial and territorial ministers responsible for seniors. Health Canada also sponsored the Invitational Symposium on Palliative Care: Provincial and Territorial Trends and Issues in Community-Based Programming in March 1997, in Ottawa. The report from this invitational symposium is available on the Health Canada Web site, "Division of Aging and Seniors."

We have supported community development for palliative care under the HIV/AIDS programming. We have also supported some developmental work on hospice palliative care that has been started by the Canadian Palliative Care Association. Between 1995 and today we have provided \$338,000 to the Canadian Palliative Care Association, a major national voluntary health organization, for their development, operating costs, strengthening their governing structure and the volunteer leadership base that is important to develop community capacity across Canada.

End-of-life and palliative care issues are also on the agenda of other health care stakeholders' organizations. For example, the National Advisory Council on Aging, which is an order-in-council body, devoted its spring 1998 issue of its newsletter, *Expression*, to issues related to seniors and palliative care. I have also left copies of that for your subcommittee. NACA, as it is usually called, also identified palliative care as a major challenges in its recent publication, *1999 and Beyond: Challenges of an Aging Canadian Society*.

In conclusion, we believe that dealing with end-of-life issues is important to ensure that Canadians have a comprehensive health system that provides support throughout a person's life. In the years ahead, we anticipate continuing to develop and disseminate knowledge about palliative care and other end-of-life issues, and we will certainly be working to help develop community capacity in this area.

Dr. Christina Mills, Director, Cancer Bureau, Laboratory Centre for Disease Control, Health Protection Branch, Department of Health Canada: The cancer bureau has a mandate to develop evidence relevant to a broad range of cancer control activities from primary prevention right through to palliative care. We aim to create the evidence where it is missing, strengthen it where it needs that, and to facilitate the use of information, real evidence, for the planning and development of policies and programs.

Palliative care is just one of six components of cancer control, but it is considered a key component. It supports the aim of improving quality of life for cancer patients at the end of their lives. Cancer patients account for the vast majority of palliative care patients.

With the aging of the baby boom population, we know that, even if rates of cancer stay substantially the same as they are now, the number of cancer patients and, hence, the number of palliative care patients in the future will greatly increase. This trend is indicated in the notes that I provided to the Clerk.

It is commonly reported that only about 5 per cent of dying cancer patients have access to palliative care. We do know that the situation has improved somewhat in some jurisdictions since those early studies, but the fact is that we do not know enough about what is going on across the country. We are aware of important geographic variations, but there has been no systematic means of determining exactly what is happening in respect of palliative care across Canada.

The activities of our bureau relate to your recommendations to strengthen research in palliative care and



to sponsor a national information program. We are bringing our grain of sand to what, we hope, will be a national information program.

The surveillance information, if it were available, would indirectly contribute to responding to your recommendations concerning national guidelines and standards, the training of health professionals, as well as the recommendation that there be an integrated approach to palliative care.

Since the original report containing the recommendations, we have co-sponsored and contributed to a number of national meetings that relate to palliative care surveillance issues. Many of these meetings dealt with precisely the issue of standards and common definitions of terms for surveillance. We have contracted with researchers to conduct studies and develop methods for the surveillance of palliative and end-of-life care.

We sponsored a pilot project to study the feasibility of collecting needed information to monitor palliative care in Canada. Six palliative care centres or programs in five cities across the country have volunteered to supply data from their program databases so that we can assess the data and determine the extent to which that would serve as the basis for systematic monitoring.

Through our Canadian Childhood Cancer Surveillance and Control Program, we have conducted a survey of parents regarding their access to supportive care and the types of supportive care provided to their children prior to death. The results of this are not available as yet.

Through our partnerships with the Canadian Coalition on Cancer Surveillance and the Canadian Strategy for Cancer Control, we have identified palliative care as one of the key components that needs to be addressed in both those efforts.

The pilot projects taught us that cancer patients accounted for more than 90 per cent of those receiving palliative care. Nearly all of these had metastatic disease. The distribution of cancer sites was comparable to the distribution of the main forms of cancer deaths.

We learned that the programs are moving towards the goal of better integration of institutional and home care. Previous speakers alluded to that goal. We hope this will enable patients to be assigned to the level of service most appropriate to their particular needs to ensure the best quality of life. Because the services are provided in such a broad range of settings, this provides a real challenge to collecting consistent and comparable information across different sites.

Programs may be partially integrated across services or may sometimes operate as parallel structures. One element that has already been demonstrated in a small way is that reducing the demand for expensive acute care hospital beds is a beneficial side effect of having these programs in place.

Through the pilot studies, we also identified an array of information needs. It seems that every time you start to collect information, you principally find out that you need more. The information is needed to plan and monitor programs and to improve our knowledge about how palliative care can most effectively be delivered. There is no information system in place, or even a combination of systems, to collect population-based data on palliative care at the national level. A few health regions may be able to provide a relatively complete picture, but there are gaps even in the best-developed systems.

We need information to follow trends in the use of services, to monitor development of new services, to assess the effectiveness of services in relation to models of service delivery, and to help plan for future services and resource delivery.





Any development of information systems will need to take into account the diverse settings in which palliative care is delivered, the local and regional nature of palliative care program development, as well as the diseases other than cancer that contribute to palliative care. As you know, AIDS and dementia are contributors to palliative care.

We need consistent and consensus-based definitions for data collection and standards of data to be able to provide information that is comparable across the country. In my brief I have outlined a couple of possibilities concerning how we can build on this. The two approaches are "incrementally", as we have been attempting to do, and "strategically", to identify where we most need the resources and to build capacity. I will not go into more detail about those.

Planning programs and developing policies in the absence of the relevant and appropriate surveillance information, compared to doing the same thing with the relevant and appropriate information, is the difference between taking aim at a target of known size and location and playing pin the tail on the donkey. In palliative care, we cannot afford to be playing pin the tail on the donkey.

Ms Debra Gillis, Director, Health Programs Support Division, Medical Services Branch, Department of Health Canada: Thank you for the opportunity to address the committee. The Medical Services Branch of Health Canada is the branch that holds responsibility for the delivery of health services to First Nations and Inuit.

Today I will provide the committee with information on steps that have been taken to address aboriginal issues raised in "Of Life and Death," that, in particular, are related to palliative care.

By way of background information, there are approximately 630,000 First Nations people and 45,000 Inuit people in Canada today. Just over half of First Nations people live on-reserve. As many of you know, health issues are of particular concern to First Nations and Inuit who experience rates of communicable and chronic disease significantly greater than those in the general population. Conditions which have become more prevalent over the past decade include diabetes, cancers, HIV/AIDS and cardiovascular disease.

While total mortality rates are similar to those of Canada as a whole, there are some exceptions. For example, infant mortality is twice as high. Death from suicide for youth is five to eight times greater amongst the First Nations population. Issues related to life and death are very significant for First Nations for a number of reasons.

The Health Canada mandate for health services delivery is directed specifically to First Nations and Inuit. All First Nations and Inuit, whether they live on-reserve or not, receive hospital and physician services through the provincial and territorial insured health services. Aboriginal people living off reserves access community-based health services, such as public health and home care, through the provincial and territorial health systems.

Health Canada, and Medical Services Branch in particular, is responsible for the delivery of community-based health services on-reserve, as well as non-insured health benefits, including prescribed pharmaceuticals and medical supplies and equipment to all First Nations and Inuit. The lack of availability of palliative care services for aboriginal people has been identified as a critical issue.

I am pleased to inform the subcommittee that Health Canada is taking significant strides to address this issue on reserve. In the February 1999 budget, funding was announced for the development and implementation of a home and community care program on-reserve and in Inuit communities. Prior to





that time, home care services had been limited to homemaking support through the Department of Indian Affairs and Northern Development and very limited home nursing provided by Health Canada. With the introduction of this new program at \$90 million per year beginning in 2002-03, First Nations and Inuit will be able to provide the full range of home care services now available to other Canadians.

While there is not a specific palliative care component in this program, the home nursing, personal care and in-home respite components of the program will go a long way to supporting individuals and their families who choose dying at home and palliative care as an option. Discussions have begun with First Nations, as they develop the home and community care programs, on how palliative care needs can be incorporated into their program.

Off reserve, First Nations and Inuit have access to palliative care programs provided through provincial and territorial health services where they exist. First Nations and the Inuit have identified that these programs need to incorporate more traditional aboriginal approaches to dying for their members and, where possible, are working with programs to do so.

Medical Services Branch also supports palliative care through its non-insured health benefits program. This program, available to all First Nations and Inuit, without restriction of residency and income, covers a wide variety of drugs used in the management of pain, including narcotic agents which are available in a variety of dosage forms, including oral and injectable forms. The narcotic drugs, as with all pharmaceuticals under this program, must be prescribed by a physician and must meet federal, provincial, and territorial laws and regulations. Thus, access to the wide variety of pharmaceuticals used in palliative care is unrestricted for First Nations and Inuit, given that they are prescribed by their attending physician.

Health Services Branch has also begun to address the palliative care needs of aboriginal people with HIV/AIDS and their caregivers. There are many instances where aboriginal AIDS patients wish to return to their home communities during the end stages of this condition. To assist the family and other caregivers, including health professionals, we have funded, in conjunction with the health program and promotion branch, the Two-Spirited People of the First Nations to produce *Nashine Ginwenimawaziwin -- Constant Care*, a manual on palliative care for aboriginal communities. This publication is widely available and used.

In closing, Health Services Branch has taken some steps to enhance access to palliative care services for First Nations on-reserve and for Inuit. I would be pleased at a later time to answer any questions you may have.

Mr. Cliff Halliwell, Director General, Applied Research and Analysis Directorate, Information, Analysis and Connectivity Branch, Department of Health Canada: Honourable senators, the Applied Research and Analysis Directorate is a new directorate within Health Canada. Its role is to support quantitative analysis, especially economic analysis, in support of both policy decision making and accountability for Health Canada's programs and activities.

Although the directorate was created in November 1998, staffing only began in the spring of 1999, and is still underway. Some research activities are now underway, mostly related to aging, health human resource issues, and health system renewal in general.

One element of the directorate existed prior to its formation, the National Health Research Development Program, NHRDP as it is known. This is a program to fund investigator-driven health research in Canada, as well as supporting young researchers through a personnel awards program.



While requests for funding to NHRDP are largely investigator-driven, Health Canada does indicate to researchers the areas in which it would like to see research done and where it would be most supportive of the research activities. To be successful, proposals must go through a rigorous peer-review process to ensure quality.

Since the 1995 committee report, NHRDP requests for proposals have included requests for research on end-of-life and palliative care issues. Some of the most useful forms of research the NHRDP funds are synthesis projects. These projects provide a summary of the state of knowledge in particular areas.

In 1997, the NHRDP released a request for proposals for synthesis projects that included projects on end-of-life and home care. The end-of-life section quoted the Senate Special Committee on Euthanasia and Assisted Suicide's recommendation that research be undertaken into how many individuals are requesting assisted suicide, why it is being requested, and whether there are any alternatives that might be acceptable to those who are making the requests.

This section of the RFP outlined two scopes of synthesis projects required. The first was synthesis of research and evidence on factors affecting the desire of terminally ill or seriously chronically ill persons to hasten death. The second was synthesis of research and evidence on chronic pain management.

The home care section focused upon providing support to informal caregivers. Again, there were two projects set out. The first was synthesis of research evidence on the effect of formal palliative care services on family caregivers' physical and mental health and well-being. The second was synthesis of research and evidence on the effects of financial compensation or payment on each of caregivers and care recipients as compared to other supports, such as community services. In total, for those two competitions, five projects were successful.

In addition, three other synthesis projects relating to the recommendations of the committee have been funded in the last three years.

As well, NHRDP has annual general competitions to look at specific research proposals in specific areas. Since 1995, the NHRDP has funded nine such projects which address the committee's recommendations. These nine do not include the most recent competition for which research proposals are still under review.

As well, through its personnel awards, the NHRDP has funded at least two researchers who have conducted work on palliative care and pain management.

In total, since 1997, NHRDP has funded around \$1.2 million worth of research and personnel awards relating to these issues. We will prepare for the committee a list of the related projects. Committee members will be free to request either the summaries or, indeed, the full studies.

To give you an idea of what kinds of studies these are, the first two synthesis projects that were funded included: "The Desire to Die or to Hasten Death in Terminal Illness: A Literature Synthesis," produced by Queen's University; and "Synthesis of Research and Evidence of Factors Affecting the Desire of Terminally Ill or Seriously Chronically Ill Persons to Hasten Death," which is out of the Université du Québec à Montréal.

In addition, the NHRDP is working to mobilize the research communities to the issues of palliative care. In its requests for 1999 annual general competition proposals, we solicited letters of intent in areas addressing issues including aging, home care and financing of the health care system.





The requests for proposals specifically called for projects addressing the integration of palliative care with long-term care. Through this competition, at least 11 research proposals were received addressing issues of end-of-life care, euthanasia, physician-assisted suicide and palliative care. These proposals are still currently under peer review and it will be some time before results are available.

The Chairman: You have given us a great deal of information. We heard in our first three presentations that little progress had been made. It is rather reassuring to hear that the Department of Health people have put their minds to the Special Senate Committee report. It is particularly good to hear that it has been used to describe certain situations on occasion. It is also fair to say that your comment that there is still a long way to go is reflective of the testimony we have heard during our other three days of meetings.

Senator Beaudoin: We are all in favour of palliative care. Who is against it? That was the feeling of the committee members in 1995. We have made some progress but we must act immediately to improve the situation. What must we do immediately in the area of palliative care? The report is now five years old. Must we legislate? Must we consult the provinces or do more? What must we do to update the report on palliative care? I have taken notice of everything you said and many things have been accomplished, but what else needs to be done?

Mr. Halliwell: Clearly, as Dr. Mills has said, better information would be helpful. We do not yet have a good sense of whether the issues that arise when these cases make headlines quite often arise when dealing with dying patients, or whether they rarely arise. The guidelines that are in place in the medical community handle quite a few of the cases that could arise.

Of course, we have just heard how difficult it is to acquire this information. It is especially difficult because these would be very sensitive questions. There is no doubt that the first step would be to try to acquire further information through pilot projects, such as those that have been described, to get a sense of the extent of the problem.

After that, I must say that this is an extraordinarily sensitive subject that touches very much upon Canadians' values. There are tremendous moral and ethical issues involved that must be dealt with at what is one of the most difficult times in a person's life, namely, when the person is dealing with the impending loss of a loved one.

I am not sure to what extent research can lead us to a better articulation of the values that should be used in making these decisions. It is something that must come out of a process that finds out what Canadians' values are in this area and tries to achieve consensus. I do not think it is an activity that lends itself to a simple approach of research or, in particular, data gathering. That would be useful, but it would not answer the questions.

Senator Beaudoin: Have you considered the possibility of enacting new legislation in the field of palliative care? Having regard to the fact that part of this problem is provincial, as well as federal, have you had meetings with your counterparts in the various provinces?

You refer, I believe, to Quebec plans and others, and Dr. Gillis referred to the aboriginal people. My impression is that we must legislate in this area, and that we must include the provinces in any discussions. Since there is unanimity on the need for palliative care, and since the provinces and the federal authority have much to do, do you think that we should legislate? I think we should.

The other day Dr. Brazeau told us that we do not need to amend the Criminal Code. I was somewhat





surprised that he made that comment, but his is a point of view for which I have the greatest respect. What do you think about that particular subject?

Ms Ouellet: Since I am the one who often has discussions with provinces on these matters, perhaps I can answer that.

We have considered, with the provinces, the issue of palliative care. In fact, one of the items that will be provided to you is a report that we produced in 1997 which was an overview of provincial and territorial palliative care programs.

The problems facing palliative care are, in many ways, synonymous with the problems provinces now face in trying to provide adequate home and community-based services for a whole array of community needs. The reality is that, within our health care system, we have taken great measures to better organize and restructure and, in some cases, even downsize our acute care system. However, we have not yet seen corresponding developments within the community and within a home setting to enable us to ensure that those people's needs will be adequately met.

I suspect -- although I do not have the data on this and perhaps my colleague, Nancy Garrard, does -- many people with a terminal illness who are in hospital would want to choose the option of dying at home, in their community, if the proper supports were available, as opposed to remaining in a hospital. We must continue to address the questions: What needs are we effectively meeting in the community in terms of care at this point; and what needs are we not meeting? From my discussions with provinces it is evident that there is considerable variability across the country in terms of what home and community care services are currently available. In almost every province those services are under stress, as we see the downsizing from the acute care sector and, at the same time, a desire not to overly increase the institutionized long-term care sector.

I am not sure that legislation is necessarily the issue. I think we must look at our system in a much more integrated way and consider how, perhaps, pressures and challenges in one part of the system are inadvertently -- or because of a delay in other initiatives -- being off-loaded onto other parts of the system that are not yet able to meet those needs.

Ms Gillis: With aboriginal people, there are two issues. One is the relationship to the new home and community care program that is being developed by aboriginal people, First Nations and Inuit. This is a major stride forward in palliative care, but it is too early to know what the issues are and how well that program will address some of the palliative care needs.

The intent of the program is full maturity within another two to three years. How communities go about addressing those needs will vary across the country. It is a little too early to know whether or not this program is addressing the palliative care needs of those living on-reserve. I think it is taking us a long way forward. Within the next four to five years, we will have a good idea of what is in place and how it is addressing the palliative care needs; what is and is not being met through this program; and then what needs to be put in place to do so.

The other issue for aboriginal people who do not live on-reserve are the same issues that Ms Ouellet mentioned, because they access the provincial health system. The strains on the provincial and territorial health system, in many ways, are reflected in the ability of aboriginal people to access palliative care services in the community. That is further enhanced by services within the provincial system that are often not culturally sensitive, as First Nations and Inuit and other aboriginal people have pointed out. That is being worked on. However, I know of instances and I have been told of instances where hospitals



are becoming much more sensitive to the needs of dying patients, of bringing traditional healers and elders into the hospital, of families being there when a person is dying, as they would in the community. Hospitals are becoming much more open to the culture and traditions of aboriginal people. That is a step forward. There is a long way to go but, I think, bit by bit, things are happening.

Senator Beaudoin: How many times a year do Ministers of Health meet, or how often do the officials, such as the deputy minister or assistant deputy minister or directors meet? There must be many meetings a year.

Ms Ouellet: Yes, there are. There are meetings at all levels including at the level of ministers and deputy ministers. There are also four senior policy advisory committees that report through that structure and they comprise a whole array of groups. In almost any given month I think it is safe to say there will be numerous federal-provincial meetings, and in between that there are many conference calls.

Dr. Mills: I wish to address the senator's previous question. Speaking as a public health physician I can say that a fairly systematic code of ethics has been developed for determining what interventions, from the public health perspective, are valid and appropriate. We look at the range of options available, including legislation, regulation, education, provision of information, and so on, and we choose the least intrusive means which will achieve the desired effect.

We know that information can be a tremendous driver for change. The Canadian Council on Health Services Accreditation now includes documentation of symptom control as part of its criteria for accreditation of health facilities. We expect that, in itself, will have an important clinical impact on patient care at the end of life because, in order to get accreditation points the health facility will have to document whether the patient was in pain, throwing up, et cetera.

In terms of the bigger system, you can draw an analogy from that situation in terms of surveillance of access to palliative care. Recently, people have been saying that 5 per cent of Canadians have access to palliative care. That may be true in some provinces but not in others. If we had good information on the actual levels of access to palliative care across the country, that would be an important driver for provinces with low levels of access to implement policies and programs which would improve access for their own citizens. If they did not take that initiative on their own, the citizens would soon make them think about doing it.

[*Translation*]

Senator Corbin: It would have been useful to have some information on the overall organization of the Department of Health, specifically with respect to health care, research, et cetera. I have observed that there are spokespersons from five different branches of the department. Should I presume that the department has other branches? Honestly, this is a bureaucratic jungle. I do not know which way to turn when there is talk about the Department of Health. Does the department have a director? Obviously, the minister, the deputy minister and the assistant deputy ministers are part of the department. However, can anyone answer this question: is there a palliative care coordinator at the Department of Health who gets all these people together on a regular basis to develop priorities, to coordinate activities in all the various fields, and to provide analysis and update us on any new developments about our sector of interest at this time? I appreciate the information you provided, but I will have to reread it and analyze your different perspectives to get a general idea.

[*English*]





Ms Ouellet: As I indicated in my opening remarks, following the release of the 1995 report, Health Canada established an interbranch committee specifically focused on reviewing and considering the recommendations from the committee's report. It looked at how our existing work within the department, which covers five branches, was already fashioned in a way that it supported these recommendations and at what other initiatives we have taken. I did not chair that interbranch committee, but the inventory of our activities, which I have offered to provide to you, is the result of much coordination and collaborative work across the department that has been undertaken since that time.

The fact that we have five witnesses here today in many ways speaks to the importance we place on the issue of palliative care and that we are trying to address it throughout the department. I believe that it is a strength rather than a weakness that five branches are actively studying this.

However, we do have an interbranch committee and we stay in touch with each other on a regular basis so that we know what progress we are making, both individually and collectively.

[*Translation*]

Senator Corbin: Have you run into federal-provincial jurisdiction problems in implementing your different programs, whether it be with the administration of services, analysis, information services? How much co-operation, or lack of co-operation, if that is the case, do you receive in your effort to establish a national palliative care system? Is this a problem?

[*English*]

Ms Ouellet: I will answer that question from the point of view of health care services, and then perhaps Mr. Halliwell would like to add something on the research side.

As one of the policy advisory committees that I mentioned to you, we have a federal-provincial policy advisory committee on health issues. This committee is concerned with the whole array of services, whether that be in hospitals, in the community, primary care, or other services. This committee meets regularly and has a very proactive agenda, including issues with respect to continuing care and home care, where a good deal of palliative care also takes place.

For the last many years I have chaired the federal-provincial working group on continuing care. My office is currently involved in some discussions with provinces on home and community care. The cooperation and dialogue are very good. All provinces and territories, which have the primary responsibility for delivery of services, rather than the federal government, are interested in learning from each other with regard to what they are able to do with their available resources, what models of delivery of service seem to work well, and what else we can learn about challenges and pressures that one jurisdiction has already addressed and another jurisdiction would like more information on.

There is a high degree of interest in good learning exchanges between jurisdictions. All jurisdictions know that home and community care is the sector which they are most pressed to grapple with as our population ages and as we undertake other changes within the health system that more and more promote care in the community. All this work has been reinforced by the commitment and by the agreement of ministers of health to make home, community care and continuing care part of their priorities. I mentioned that they initially agreed upon this in 1998. They reinforced it as a definite priority for collaborative work, as well as work within their own jurisdictions, when they met in September 1999.

Therefore, the cooperation is there. Individual jurisdictions face their own unique challenges, challenges





that the jurisdictions themselves will certainly need to address. There is much that we are already learning from each other. There is also a good platform on which some collaborative work is being undertaken.

[*Translation*]

Mr. Halliwell: In the research, and more specifically, in the information services, there is a climate of co-operation. All of the projects funded by Health Canada are in the public domain, and therefore can be consulted by anyone who wishes to do so. We might be able to do a better job when it comes to publicizing our work. This information is available to all the provincial authorities.

In the research field specifically, it may be possible that the provincial departments, because of budget cutbacks, are limiting their study of research projects undertaken in the communities, specifically those undertaken by university researchers. This problem should be fixed now.

The Canadian Health Services Research Foundation is doing a lot of work to facilitate the exchange of information between researchers and governments. The Foundation demonstrated that this service was under-utilized once the research projects had been given a go ahead. Most of the information comes from three main sources: Statistics Canada, Health Information Services of CISTI and administrative databases, mostly provincial. There has always been a tradition to share this information when it is possible, however we have to respect the confidentiality principle, especially given the field of health.

However, it is not easy simply exchanging information with other researchers. For example, many of Statistics Canada's detailed databases are not readily available at Health Canada.

Senator Corbin: That is an important issue, and you should have access to this information to complete your research. How do you get around these problems?

[*English*]

Ms Leslie Gaudette, Section Head, Treatment and Palliation Section, Cancer Control Assessment and Surveillance Division, Cancer Bureau, Laboratory Centre for Disease Control, Department of Health Canada: We recently met with representatives of our palliative care centres. As a result, there are two points I wish to make. The first has to do with the level of the organization of the services and the effect of that on our ability to measure it. The second has to do with some of the databases, and so on, that Dr. Halliwell has mentioned.

What struck me when we were meeting with the centres -- and you will be hearing from one of them later this afternoon -- is that they are very much local organizations. They are community based. Perhaps, if we are lucky, they might be organized and coordinated at the level of the health region. I cannot speak about what goes on at the provincial level. However, there is clearly no provincial level of data collection in most provinces. That makes it a lot different from most of the data systems we have in Canada, where the collection goes from the province to a national organization, such as Statistics Canada, the Canadian Institute for Health Information or Health Canada.

Because the care crosses from home care to institutional care, those data sets are quite differently organized. There is, perhaps, good information from the institutional care side but not from the home care side. That makes it difficult to get a picture. As we were analyzing our data, one of the major issues was trying to track the patients through various types of institutional care settings and the home care setting, to come up with a complete picture. Even though many patients may want to die at home, some



may be in situations where they need to be in a hospital setting.

I would like to address the issue of the administrative databases. I am presently on secondment from Statistics Canada, where I worked extensively with the Canadian cancer registry. We have excellent data on the incidence of cancer and mortality. We are getting data on survival. We have hospitalization data, which are linked within Statistics Canada, that allows us to get care records across patients from about 1992 onward. We have just signed a contract with Statistics Canada so that Health Canada can actually go over to Statistics Canada to conduct further analyses. One of the areas we will be looking at is palliative care.

In terms of statistics, there is a huge gap where home care is concerned. However, the Canadian Institute for Health Information is developing databases that are not yet in place.

Dr. Mills: This brings me back to Senator Beaudoin's question about what kinds of things could be done. A number of years ago, I did a key informant survey in Ottawa-Carleton about the needs for palliative care in the region. One of the key findings that came out of that survey was that there was a need to find some way of ensuring that patients did not fall through the cracks when they went from the home to the hospital, back to the home, to the hospice, or perhaps to an emergency ward for some particular thing. They kept getting lost because there was no single information tracking system. There was no simple way of tracking this information. Some people suggested that a smart card could be used for this purpose. The need for such data is that these people do not stay in one setting all the way through their care. They move across settings. The obstacles to getting coherent data collection, even administratively, are immense. They simply reflect the obstacles to good, continuing, coherent and comprehensive care.

*[Translation]*

Mr. Halliwell: I agree with Ms Gaudette. Statistics Canada is very much aware of the problem and is working at solving it, so that researchers could have access to the databases. In fact, thanks to the Data Release Project, academics who are working on research projects will have access to the Statistics Canada databases as though they were themselves employees of Statistics Canada.

One of the priorities of the Department of Health, in the field of data processing with the provinces, is to promote the development of a method to identify Canadians when they use the different health services by providing them with an identification card or an identification number. This would lead to much more thorough databases and better links between them. This is more important for the client, but it would also be an important step to providing better access to these big administrative databases for research projects.

Senator Corbin: Can a change in minister affect the nature of your work, in the sense that research or support or service delivery in one field might be favoured over another, and might this be the case more specifically when it comes to palliative care?

If a minister told you that it was important that the department focus quite seriously on one service in particular, on the deficiencies, the opportunities, the regional deployment, and the level of inter-governmental co-operation that would need to be established to ensure a good palliative care system in Canada, I presume that all of the department's bureaucracy would do what it had to do in order to respond to the expectations and the wishes of the Minister.

Is this in fact how it happens? Or is it each branch which decides how important a report such as the Senate report on Palliative Care is? Who is it who makes this type of policy decision?





I do not mean to point the finger today, but I have the feeling that despite all the work you have done and all the progress that you have made, things aren't happening fast enough. Could you please tell me about the political and bureaucratic relations in a field such as this?

[English]

Where do you get your marching orders? Are there marching orders?

The Chairman: That is a difficult question for any of you to answer. Perhaps Ms Ouellet could give it a stab.

Ms Ouellet: As a policy branch, we like to think that we have some sense of that.

Clearly, the department has a large mandate and a huge number of priorities. In part, our structure reflects, through our business lines, the fact that we have tremendous pressures and priorities in the areas of risk management and services to First Nations population health and health care. Within the department, there is no doubt that we do need to manage our efforts and resources in all of these areas and probably could not neglect our statutory mandates in this regard.

Having said that, when ministers set priorities, those priorities are, of course, taken on extremely seriously by the department. In fact, we work to present the minister with options and initiatives that will respond not only to the direction of those priorities but to the urgency and speed with which ministers determine that they want to see actions move forward.

Ultimately, our role is to provide good analysis and good advice, and there are any number of other factors that come into play in terms of how quickly initiatives can be moved forward. These include our own resources, our own capacity, and the extent of agreement with provinces and territories. As I am sure you realize, because health care is a provincial jurisdiction, the federal government's role is one of support, facilitation, and leadership, but in conjunction with and very much in collaboration with provinces and territories.

The Chairman: Considering the delicacy of that question, I appreciate your answer.

[Translation]

Senator Pépin: I hear you all talk about the excellent co-operation between the provinces. However, if we are to believe what the witnesses told us last week and what the newspapers reported on the weekend, there are three problems: physical access to the centres, unavailability of drugs to everyone, and shortage in home care workers.

It has been said that depending on the region or the province where you live, you do not or will not have the same care. One of the things that we are looking at is how to ensure that people living in Halifax, Quebec City, Toronto and Vancouver, will have similar services and similar access.

True, co-operation is lovely. However, on the practical side, if you keep both feet on the ground, how can this be organized and how can you coordinate this care? From the testimony we have heard up until now, the quality and the access to this care, as well as the availability of good drugs, depend on the region in which you live. What can we do in order to help you with this job and, more important, so that everyone can have access to the same level of palliative care?

[English]





Ms Ouellet: In many ways, we have uncovered, as part of our documentation of the existing home and community care programs, much of what you talk about. Different provinces currently offer quite different access, at least in terms of publicly covered services. In some provinces, the access to services will concentrate primarily on professional services, and within that, primarily nursing services. In other provinces, other jurisdictions, they may have a very comprehensive range of services.

In many ways, the state of our current home and community care services has depended upon a number of things. It has depended upon how the provinces themselves have chosen to organize their own health systems, where they have chosen to put the emphasis, and in many ways the resources that they have had available within their health budgets to develop the home and community care sector. In other cases, it has been perhaps a matter of a decision, politically or otherwise, in terms of what should be the role of the public system versus the private system.

Home and community care is also an area where one sees a very high level of privately provided services. Much as my colleagues have been talking about information, while we do not have good information on the publicly provided services, our information on private services is much less -- although perhaps not quite zero. Finding the information would involve interacting with a number of private providers at a community level all across Canada. It is very difficult to have a handle on what those services are.

From the point of view of what we can do to facilitate and promote the availability of these services, the federal role is to work together with the provinces to identify what are the issues and challenges, and which of those issues are more national in their context. Certainly, some of the challenges with respect to health -- human resources, providers, professionals -- are issues that are common across jurisdictions, as are issues with respect to information systems and the quality-of-care standards. We are attempting to work with the provinces to deal with some of those national issues.

In so doing, we find that, at least conceptually, there is quite a degree of consensus about the kinds of home and community care services that we would like to see in the future. At this point, there is a question of resources within the jurisdictions. There is a question of other preoccupations with other pressures faced, particularly on the hospital side. Some jurisdictions, therefore, are prepared to move faster than others in this area.

The minister's impetus to bring his colleagues together to talk about this is one of the ways in which we can help move the discussion along. Federal and provincial ministers already agree -- and this would have been the piece of the discussion that you would have missed -- that this is an area of priority. They realize that this area of the system is under the most pressure and will feel most the implications of an aging population. We need to look at this sector and improve services; but at the end of the day, the decisions on how those services are delivered and organized and how quickly those services can be expanded to meet the needs of Canadians will rest back with the provinces.

*[Translation]*

Senator P  pin: It is not unusual these days to see members of a family leaving their home province to go and work in other provinces. So it is quite probable that they would suffer from similar health problems and yet not receive the same care because that care varies from one province to the next.

*[English]*

Ms Ouellet: That is true and it is because of another complication within our system. Many provinces.



with the exception of Ontario, have chosen to regionalize the service delivery. In effect, this means that the provinces provide regional health authorities or community health boards with global budgets to provide services to their populations. One can see variability at a regional level within a province, depending upon how that particular region has assessed the needs of its constituents and how it has chosen to emphasize some services and not to provide other services.

Within a general overall accountability framework, there can be some variability even within provinces.

[*Translation*]

Senator P  pin: Could we find the same thing here with the use of certain drugs? Could one province decide to restrict the use of certain more costly drugs unless the patient has private insurance? Are some provinces more likely than others to use specific drugs?

[*English*]

Ms Ouellet: Certainly, we will find some variability between provinces in terms of their drug plans for publicly covered drugs. Within a province, however, because that is still managed at a provincial level, eligibility and co-payments or deductibles would be consistent across the province.

Ms Gillis: I had mentioned earlier that the province of residence is not a determinant for whether a First Nations or Inuit person can access any drug. It depends on the prescribing physician. Any drug prescribed by a physician that relates, especially, to pain management and control in the home would be funded under the non-insured health benefits program for First Nations and Inuit.

There is a wide range of drugs on the formulary. If a drug is not on the formulary because it is usually of very limited use, we do have a process whereby the physician can apply and receive a quick turn-around through a drug centre. In speaking to the people within the branch who manage the program, the pharmacists say that, on such issues, the people are not refused or turned away. People do have full access to the drugs.

The Chairman: Dr. Mills, you said that 90 per cent of palliative patients are cancer patients. One of the things we talked about in our original report was the need to broaden palliative care to cover not only cancer patients but also victims of ALS, Alzheimer's and other diseases. I gather from your information that you do not think that that has happened to any great degree over the last five years. Am I correct?

Dr. Mills: It is not so much that there is any preferential delivery of palliative care to cancer patients. Rather, cancer is so much more common than any of those other conditions; it tends to occupy the capacity for care. Canadians have a 1 in 3 chance of developing cancer in their lifetime. That is a lot of people with cancer at any given time. Of those people with cancer, a certain proportion of them will be requiring palliative care compared to any other condition that ends up requiring palliative care. For the foreseeable future, cancer patients will be the dominant clientele of palliative care. Of course, you are right; it is not the only clientele and we must ensure that the services are appropriate for all people who need palliative care.

The Chairman: We actually found anecdotal examples in our previous study where people could not access palliative care, even if they needed it, because they did not have cancer. The criterion at the door was this: If you have cancer, you get palliative care; if you do not have cancer, tough.

Ms Gaudette: Of the six centres that we studied, only one specifically restricted its program to cancer





patients. Most of the programs did accept other patients. There were some interesting discussions around the table a few weeks ago regarding the relative need of cancer patients for palliative care.

Metastatic cancer is often associated with severe pain. It is a prolonged process and the curative cancer treatment is normally provided in a central cancer agency for therapy or in treatment centres that may be a long distance from the patient's home. Towards the end of a cancer patient's life, he or she is usually treated nearer their home and so may be moved to a palliative care setting if they are lucky, as you say.

The Chairman: Ms Gillis, with respect to aboriginal care, I was somewhat surprised -- and maybe I did not hear you correctly -- to hear you imply that this program for community-based care will not take effect until 2002-2003. Did I hear you correctly?

Ms Gillis: The program was announced at \$152 million over three years. The funding ramps up. The ongoing funding begins in 2002-03. This year, there is funding and they are beginning their planning. Next year, there will be more planning, development and service delivery in areas that are readily available. That includes training of all the health workers, addressing some of the capital needs, and so on.

While services will be delivered as the program is being developed, each community will be developing as needed at their own pace. However, the full funding does not come into place until 2002-03.

The Chairman: I am from Manitoba. All aboriginal children in Manitoba who have a serious illness are brought to the Children's Hospital in Winnipeg. In many situations, an aboriginal child cannot be returned to his community because there are no services in place in that community.

We all know that acute care hospital beds represent the most expensive health care delivery system; we do not have to go through that argument again. That is a given. However, we use the most acute care to look after an aboriginal three-year-old who would be happier and would have more stability in his life if he was home in his aboriginal community. I assume that those are the kinds of things you are attempting to address; correct?

Ms Gillis: You are absolutely right. In Manitoba, in particular, Medical Services Branch, Health Canada, the Department of Indian Affairs and the Province of Manitoba have initiated a special program related to First Nations in Manitoba. The program works with a number of children who have needed high levels of medical care and have been placed in hospitals and in special care for a period of time. The mandate of the program is to move these children back to their home communities and to put in place, in many instances, 24-hour support services. This is a special pilot program outside of this new home care initiative.

In addition, there is a significant amount of pressure in First Nation communities -- they want to get this program off the ground quickly. They also recognize the importance of planning the program well, ensuring that the foundation is well based so that the program can continue into the future successfully. There are great pressures, and communities are feeling those pressures. We are working with them to help move this along as quickly as possible.

The Chairman: Perhaps some of the letters that I wrote will have an effect. One never knows.

[*Translation*]

Senator Beaudoin: When it comes to health, federal and provincial government relations are very





important. Each has a role to play, the federal government, for example, when it comes to the criminal code, spending power, et cetera.

You say that there are monthly meetings between these two levels of government. What are the provincial governments telling you? Are there conflicts? Are they satisfied with what is happening across the country? I presume that provinces do not all have the same system, some of them may have more money and find it easier.

Canada is recognized around the world when it comes to health care, but there is no such thing as a perfect system. What do the provinces criticize, and what do they praise?

[*English*]

Ms Ouellet: That is a big question.

Senator Beaudoin: You may restrict it, if you wish.

Ms Ouellet: When I said that we meet monthly, this obviously is not the same group that meets that frequently. What I meant to indicate is that there is, within the structure of federal and provincial committees in health, committees of ministers, a committee of deputy ministers, and four advisory committees. Within those structures there are also some subcommittees on specific topics, one of which is the topic that we are discussing today, home and continuing care.

In order to do the business of trying to advance work in health and, more particularly, in the health system across the country, these committees do meet very frequently. The mandates obviously flow from agreements of ministers and, in this particular case, there is no argument that home and community care is a priority and that this is something that we should work on. In fact, that has accelerated in some ways the frequency of our meetings and of our conference calls on this particular subject.

Essentially, provinces want to know what we can help them to determine about what works and what does not work in terms of effective models for delivering care. Provinces are interested in looking at what kinds of cost efficiencies they can build into the system. Therefore, for example, in this area, we have a study that we are funding through the health transition fund, which I have mentioned already, that is looking at the cost effectiveness of home and community care: For what patients and in what situations is this cost effective, and when is it not only not cost effective but not appropriate in terms of the levels of need of the patients?

We assist the provinces with supporting demonstration projects with research. We help to facilitate the exchange of information. We help to develop strategies on moving forward, even when those strategies are really primarily within their own jurisdictions, and it is up to individual provinces to decide when and how quickly to move forward on those initiatives.

By and large, the difficulty is that, while the challenges are quite common, the provinces are at different points in terms of the development of their own systems, and their readiness to move forward is not all at the same level at the same time. However, where we can, we support that. Enough funding for health care is always an issue, but even the provinces would say that more funding to do the wrong thing is not what we want to do.

We need to determine what are the best ways to develop this sector so that we know that we are meeting the needs as best we can within available resources. We know the quality of care is good and we can



monitor and assess the quality of care that people are receiving in the community. We know that this part of the system is becoming more and more integrated with other parts of the system so that as you leave one setting you do not fall between a crack until some other setting finds you and begins to offer you care.

On a strategic and practical level, there is work that is underway that will be helpful. At the end of the day, the federal government can certainly play a role in collaboration with the provinces in most instances.

The Chairman: Thank you very much. I thank all of the panellists today. We are hoping that you will be available for us perhaps on another occasion if we have more questions, either by letter or by personal appearance.

Ms Ouellet, you promised us a summary on the interbranch committee with respect to some of the work that we have been doing.

Mr. Halliwell, you indicated that you would be giving us some summaries -- and then full studies, if honourable senators would then like the full studies. I have already seen some of the studies from the NRDP.

If any of the rest of you think that there is material that would be useful for our deliberations, please do not hesitate to send it to us. I will ensure that it is distributed to all members of the committee.

Senator Corbin: Before Ms Gaudette leaves, I wish to raise a grievance. Members of Parliament who wish to obtain analysis from Statistics Canada must pay for it. I have had to pay for information from Statistics Canada. You now tell me that university researchers, under the guise of being associated with Statistics Canada, can access your information banks at no cost.

We heard earlier that a client department like Health Canada has a contract with Statistics Canada. I do not know if there are costs incurred or not. However, Madam Chair, in the pursuance of our duties and our work as responsible members of Parliament, I do raise a grievance that we should not have to pay for information that is crucial to our evaluation and assessment of government programs.

The Chairman: Your grievance is heard and I am sure that, at the appropriate time, the appropriate people will be told. Thank you all very much.

Honourable senators, we are extremely fortunate to have with us some guests from the Elisabeth-Bruyère Health Centre. Any of you who live in the Ottawa area understand the positive work they do there. I have known some people who have been there and who have died there. On behalf of them and their families, I wish to thank these witnesses and the staff of the Elisabeth-Bruyère Health Centre for the wonderful care that is given.

With that personal endorsement, we have at the table today Dr. Ray Viola, Dr. Cori Schroder, Ms Maryse Bouvette, and Ms Diane Hupé, who are all with the Palliative Care Program.

Ms Maryse Bouvette, Nurse, Coordinator, Pain and Symptom Assessment Team, Palliative Care Program, Sisters of Charity of Ottawa Health Service: Honourable Senators, we represent the Regional Palliative Care Centre, which includes 45 palliative care beds located at the Elisabeth-Bruyère Health Centre, which is part of the Sisters of Charity of Ottawa Health Service. This also includes a 24-hour phone consultation service and a home consultation service, as well as the Institute of Palliative Care.





All three components are part of the Regional Palliative Care Centre.

One way to share some of our experience and concern with you is to describe a specific case. We hope that taking you through this case will give you an appreciation for the type of concern we feel. This case involves a 45-year-old mechanic named John. He was diagnosed with cancer of the lung. He has two children, two boys aged 12 and 15, and his wife works part time. When he first received his diagnosis, he was treated with surgery and chemotherapy, as well as with radiation treatment. He is now having a recurrence of his disease, and his oncologist offers him a second-line chemotherapy treatment.

The real goal of this chemotherapy treatment is symptom treatment and symptom prevention. There is a potential for the prolonging of life of approximately a month or two, but John decides to decline that second-line chemotherapy because of all the side effects he had from his first experience with chemotherapy. His oncologist refers him to the palliative medicine clinic at the cancer clinic so that he can get advice on symptom management and pain management and also be provided with information around palliative care or related to palliative care issues.

A month later, John is presenting with major shoulder pain. The pain is moderate to severe, it is burning, it is sharp, it is there all the time. The pain prevents him from sleeping because it is bad during repositioning. It is worse during coughing. It is also worse during deep breathing. The family physician recommends a chest x-ray to see what is happening and prescribes some regular morphine and, on an as-needed basis, a dose of morphine to help with his pain. He also seeks help from the palliative medicine clinic where John was seen in the first place. The family physician requests and obtains a consultation with the physician from the palliative medicine clinic.

John is seen by the palliative care physician, and the x-ray shows a large mass involving the ribs, which certainly explains some of the symptoms he has been presenting with. Other symptoms, such as nausea and constipation, are also recognized. The palliative care physician recommends increasing the dose of morphine and adding some co-analgesics, medication that is not really an analgesic but that could help with some pain. John is also to have another assessment with the radio-oncologist for some potential radiotherapy that could help with symptom control.

At the same time, as the picture is worsening the family is having a hard time, and so is John. It is a good time to have the Community Care Access Centre involved. A nurse was not needed previously, but now one is required to check regularly on his symptoms and pain, and a social worker is involved to help with psychosocial and spiritual issues. A physiotherapist is also on-board to help with positioning and to bring a non-pharmacological approach to help with pain management. The family is also offered volunteer services through the hospice involved.

John and his family are willing to accept any kind of help because they really need it. The wife is still working, so it is great help to have all these people come into the home to help and bring a sense of security that John is not alone for a long period of time.

Despite the fact that the symptoms improve, John's situation continues to deteriorate. As John becomes weaker, the family physician agrees to do home visits. Another symptom arises: a bad case of shortness of breath. It causes a lot of anxiety. At this point, the family physician asks for a home consultation to help the situation. The nature of the symptom is causing a lot of anxiety and the family wants it corrected. The palliative consultation team goes into the home and addresses the symptom of shortness of breath by administering morphine via a pump for a continuous delivery of medication and adding medication such as steroids and some oxygen to it. The nurse is there to teach the family about non-pharmacological approaches to control the anxiety, such as relaxation breathing, companionship and





relaxation. That certainly helps, as does some medication administered to lessen John's anxiety.

John's wife then decides to quit her job because it is necessary for her to be around John a lot more. This causes some financial issues. However, the social worker is there to try to assist with that, as well as to support the two children. As time goes on, John becomes less and less conscious and John's wife is very worried that he is not eating or drinking that much. The idea of dehydration is then an issue. To address it, we are able to bring about some hypodermoclysis -- that is, hydration under the skin -- in the home setting. That helps the wife to know that at least he is not dehydrated. We also have to look at the benefit versus the burden of this procedure. It is done with the idea that if it does not help, we will discontinue the procedure. The nurse also undertakes a close follow-up on the mouth care -- that is, the good hydration of the mouth -- and teaches the family how to do it as well.

Things settle down until the next symptom arises: agitation and restlessness, which we call delirium. Again, the family physician is able to access palliative care expertise to look at the management of it in the home setting, which works well.

It was decided at the beginning of the disease that John wanted to remain home for as long as possible, but he did not want to die at home. Although his symptoms are under better control, his deterioration is obvious, so there is a planned admission to a specialized palliative care unit. John dies three days after his admission to the palliative care unit. After his death, some work remains to be done with the family. Bereavement support is available not only through the hospice setting but also through the specialized palliative care unit by phone calls, by memorial services, and by bereavement support group.

That is but one story. They are not all that well coordinated, but it would be preferable if it could always happen like that.

I am here to share with you the clinical care and the team work that is required for the care of a person who is diagnosed with a terminal illness. I have some key points with which I should like to begin. First, there are the patient's needs. Patient and family are part of the team, so they need to have access to information and to have a chance to share their concerns so that they can have and make informed decisions.

Second, access to interdisciplinary palliative care expertise is essential. Patient and family represent a unit of care. We need to be there to help them follow their goal. "Quality of life" depends on their own value of that phrase, and it is very individualized. The health care team members are key to recognizing the needs and initiating the services that are available, when they are available. Ongoing collaboration between the oncologist and the family physician is crucial. An interdisciplinary and holistic approach is essential to address their needs. "Holistic" means overall -- not only as a person in a body but also as a psychosocial, emotional and spiritual being.

John's case can be used to bring out some of those points. In this case, John was well informed. He had options. He decided about his treatment, about where he wanted to journey with his family, and about where he wanted to die. Often, dissatisfaction related to patient care is due to the fact that people are not always well informed and they do not have a chance to make that decision.

Family physicians are essential. Individuals cannot dream of dying at home if there is no family physician with them in a home setting to do home visits. However, many physicians neither feel comfortable with that nor want to do home visits. In my experience, I have learned that, sometimes, physicians will change their mind because they realize that they have a service there to help them. It is an attitude, almost, that we must change.



The primary care team must have access to expertise. We cannot expect everyone to be an expert, but we can learn. The number of palliative care patients that a family physician may have in one year may not be enough that he can maintain that expertise. However, knowing that there is a team to back up a physician may help a lot. John was privileged in that he was able to access the service and he was well treated at home.

Pain symptom management must be addressed holistically. You may have heard of the principle of total pain. We have been focussing on physical pain, but physical pain can be worsened by psychosocial and emotional issues. That means that a portion of that physical pain can be alleviated by addressing those issues, and not only by using pharmacological approaches.

Collaboration and communication between the family physician and the oncologist is essential. Often, that is what happens in reality. A patient is followed by his family physician. He is diagnosed with cancer and then he is followed by a specialist for a period of months, maybe years. When he reaches, say, the palliative care phase where there is no more chemotherapy to be offered, then what does he do? He returns to his family physician, where he has lost contact for the last few months or years. This is not a seamless system. We need to have the continuity, collaboration and communication between the family physician and the oncologist or specialist.

The interdisciplinary resources must be made available. We may recommend that you need a social worker and a physiotherapist at home, but is that service available out there in the community? Furthermore, are we suggesting things that are not available? We must ensure that they these services are available.

Optimal communication among the patient, family and all the care system is also important. The case that I related to you is a good example of the fact that when good communication happens you can have a good result. The symptoms were well addressed, the care was increased as the disease progressed, and the communication was well established.

There is no ideal place to die. The ideal place to die is defined by each of us, depending on our experience and values and our actual status.

I cannot say how important bereavement support is. It is not because the life of this person has ended that everything is a fait accompli and great. There are still lives happening and they are bringing with them some heritage. We need to ensure that we are there to help them journey and find some meaning. Sometimes, it takes a lifetime to find meaning in events that are happening to us. Certainly, by sharing and remembering, we can help those family members remaining to live better and perhaps have a better attitude towards life in general.

Dr. Cori D. Schroder, Physician, Palliative Care Program, Sisters of Charity of Ottawa Health Service: I am a palliative care physician. I provide clinical care to patients on the unit and as a consultant within SCO. The other hat I wear is that of an educator. As I have a great deal of interest in providing palliative care education, I should like to look, focusing on the case, at the educational and training perspective.

When I think of an overall goal for palliative care educational programming, especially in regional terms, since as we do it on a regional basis here that is what I am familiar with, it is to raise the general skill level of all health care providers and ensure ongoing competency so as to improve the delivery of palliative care to all dying patients in the region. I think there are difficulties and challenges with respect to palliative care education and training. Some of those relate to an appreciation of the complexity of the care that is encompassed by palliative care. Not only does this care involve the physical domain of pain





or symptoms, but also the psychosocial and spiritual domains.

Another aspect that adds to the complexity of palliative care is the changing focus of its requirements. Initially, palliative care had a cancer focus, but we are now expanding and looking at other patient populations who suffer from chronic diseases such as end stage heart disease and lung disease, musculoskeletal disease and neuromuscular disease. Gaining sufficient knowledge in those areas has created difficulties. How do we take what we have learned in cancer care and end-of-life care and apply that knowledge to people who have other chronic disease processes?

I believe another aspect of the complexity of care is the setting in which care is provided. We have heard, too, that palliative care goes across settings. It is not only institutional care, but also care in the community, whether within an urban or rural centre, and that adds to the complexity of what we need to teach.

The process involves the acquisition of the appropriate knowledge and skills to take care of these patients. I think of key importance is attitudinal learning, which is extremely difficult. Looking at the issue of pain management, we have spent years training and teaching people about how to use opioids and analgesics appropriately. Until we start changing attitudes, palliative care levels will not progress. We are seeing studies that show that people are not getting good pain control. We are reminded, however, that changing attitudes does not occur quickly and it also does not occur using the lecture method that is the standard approach to education.

I believe that education training in palliative care needs to teach people how to collaborate and work in a team. You have heard about the virtual team in the community, certainly the teams within palliative care units, but people need to be taught how to work in teams and how to collaborate their efforts. That does not come naturally. We need specialty training. It is great if all our health care providers have some basic training, but you need the experts to provide resources in consultation, in education and in research.

We need to evaluate outcomes. We do not know how effective the existing educational programs are because they are not evaluated. The ultimate outcomes must produce benefits to the person in the community who is dying. Only then, once we have evaluation, can we disseminate effective approaches to education.

Last, in looking at regional programming, we certainly need community participation in the planning, the implementation and the evaluation processes. In this particular case, the medical oncologist and the family physician showed attitudes of care versus cure. They showed the importance of sharing the care, of collaborating and of good communication. They had basic symptom control knowledge and sensitivity to the non-physical issues, such as psychosocial and spiritual issues. They were aware of resources and when to use them well, and they were able to function within a team.

Where did they learn how to do that? Unfortunately for undergraduate medical students, there is no consistency as to the presence, format or topics for palliative care education, despite the recommendation in the 1995 document. Training as to how to function as a team member to solve complex problems does not exist either. There are some post-graduate medical training programs that do have mandatory palliative care rotations, but, again, the teaching is not consistent. Many, especially family physicians who are going to do the bulk of the care, are not even guaranteed any mandatory training in palliative care. Again, training to function as a team is non-existent.

In respect of continuing medical education, we have, in Ontario, a few small initiatives, but since each year they are still considered initiatives, we never know whether or not the funding is going to come in.





These initiatives are sporadic at best, applied differently in different regions and limited by the lack of funding. They are not specific to settings. For example, someone may develop an initiative that works well in an urban centre, but teaching people in rural centres remains in question because the setting of care and what is available to them is very different. There has not been an evaluation of the existing Ontario initiatives because there is no funding and so no interest in doing that at this time.

The palliative care consultant shows expert symptom control knowledge -- again, holistic care. This consultant is very supportive of the primary care team, acts as a resource and an educator, and is very much able to function within the team. Where is this learned? A few centres have been offering post-graduate training. Recently, the Royal College of Physicians and Surgeons of Canada and the College of Family Physicians of Canada have conjointly accredited a program of post-graduate training in palliative medicine. Seven out of fifteen faculties have applied for the program, but there is no funding attached to it.

Senator Corbin: What do you mean by that?

Dr. Schroder: There are no salaries for the residents and no specific funding to build the infrastructure related to that particular program.

The interdisciplinary team members who care for John and his family are as important as the physicians. They demonstrate attitudes of care versus cure, basic understanding, knowledge of palliative care as related to their scope of practice, and the ability to function as part of a team. We do not know where they received such training. For nurses, social workers, pharmacists and pastoral caregivers, there is no mandatory palliative care component to their training. There is limited continuing education, and interdisciplinarity is not taught. For non-professional caregivers, such training is even more limited. We need basic competency of all health care providers to ensure that all people have the quality of care experienced by John. We need funding for specialty programming, and we need support for initiatives that are going to provide the training opportunities to all health care providers. The training must be setting-specific and must reflect the interdisciplinary nature of palliative care. Above all, we need evaluation of the education training programs currently in place in order to assess their effectiveness.

Dr. Raymond A. Viola, Physician, Palliative Care Program, Sisters of Charity of Ottawa Health Service: I will address the research and evaluation components of palliative care programs in this country.

Health care progresses and improves because of research and evaluation. When those do not occur, health care languishes and becomes irrelevant to the population it serves. Research may be simple, such as clinical observation and documentation, or it may be quite elaborate, such as multi-centre randomized control trials.

Palliative care is a young and still developing area of health care that has made great progress in a relatively short time because of the ability of the clinicians in this field to be innovative in caring for the dying and to observe carefully the apparent effects of the innovations they implement. In this way, for instance, the treatment of advanced cancer pain was revolutionized during the last 30 years. The effectiveness and safety of treating John's pain with morphine and other medications was informed by the vast experience of palliative care clinicians during the past three decades. The use of regular doses of morphine by mouth, the use of rescue doses of opiates, the gradual incrementation of doses, and the use of continuous infusions of medications have all evolved from clinical practice, innovation, dedication, observation, documentation and reporting by clinicians caring for the dying.

A similar elucidation of therapies for assessing and managing other symptoms has occurred. For



instance, troublesome and frightening shortness of breath is a common symptom experienced by the dying, as John experienced. As well, delirium is very common as death approaches. Advances have occurred in the assessment, prevention and management of these problems, although not to the same extent as has occurred for pain. Weakness, loss of appetite, and loss of weight are enormously common in the dying, occurring for months before death. We are not yet close to being able adequately to help dying persons who endure those problems, nor to help them live satisfactorily with the severe debility that results.

The question of whether fluids should be provided by needle when a person is close to death and has limited intake by mouth is controversial and was faced by John's family and professional caregivers. Understanding the specific clinical issues is important, but equally important is understanding and supporting the decision making of patients and families facing the end of life. That has only started to be explored in a systematic way by end-of-life researchers, and much more work needs to be done.

The impact of caregiving at home by the family of a dying person is enormous, with some of the effects described in our attempt to tell John's story. However, a detailed understanding of the best ways to help families provide this care, especially in the post-health-care-restructuring era, is urgently needed. What are the effects of caregiving on the bereavement of adults and children? What are the short- and long-term financial implications? Which services are needed and which are redundant? How can the patients' and families' preferred places of care and death, most often the home, be realized? How can we best help survivors before the loved one's death and then during bereavement? All of those questions are faced daily by palliative care teams and researchers.

However, most, although not all, end-of-life research that has been carried out has been at the level of clinical observation and anecdote. That has not changed much in Canada during the past five years. Carefully planned and executed studies providing stronger evidence of therapeutic effectiveness or of the multi-dimensional experiences of the dying have been difficult to carry out. Much of the evidence we rely on to treat physical symptoms is extrapolated from stronger research done with other populations of patients. The applicability to the dying is presumed, but not proven.

For continuing progress to occur in the care of the dying and their families, there is now a need to carry out a much larger volume of research and to plan studies that provide valid, reliable and generalizable evidence pertinent to the care of the dying. There is a need for this research to be done in Canada so that it can be applicable to the Canadian health care system and Canadian society. Along the same lines, programs also need to participate in high-quality evaluation processes for the services they provide.

Obstacles to palliative care research are numerous and include the following: the belief that research with dying persons and their families cannot be done; ethical concerns that such research should not be done; the lack of adequate, specific funding for research in palliative care; the lack of trained researchers in the field; limited access by researchers to enough dying persons to carry out the studies; and the lack of relevant, practical and validated outcome measures.

Research with and for dying persons can and should be done. Otherwise, we will never know how to improve the care of the dying and their families and how best to address the complexities and the interactions between the physical, psychological, social and spiritual aspects of suffering.

Research and evaluation are occurring, although in relatively limited amounts and only in certain settings. Some progress has been made in developing outcome measures relevant to palliative care, but the progress overall has been slow. Research has become much more acceptable in palliative care settings during the past few years, but the palliative care team's ability to do the research and evaluation





is limited. For clinical programs to carry out research and evaluation, they require researchers with appropriate training and adequate protected time. Without that, clinical and administrative work dominates the time available so that research is not addressed. Most programs have limited funding that barely allows for the clinical work to be done, let alone the education, research and evaluation. The few existing protected researchers often have to work on their own, with few additional resources and with difficulty accessing consistent research project funding.

For end-of-life research to advance, funding must be available consistently to programs that can lead the research. Currently, most funding is internal and, hence, limited to a few programs and small amounts. The training of researchers who are interested in end-of-life care must be increased so that appropriate expertise is available to lead this work. A network of palliative care programs across the country must be developed and supported so that studies involving enough patients can be successfully completed to provide definitive answers to important clinical and health service questions. Recently, such a national network received \$60,000 per year of infrastructure funding from the Canadian Cancer Society and the National Cancer Institute of Canada, part of the Sociobehavioural Cancer Research Network. That is a small start.

Clinicians, researchers, patients, families and the public all need to take part in the research planning so that relevant, valid, efficient studies are undertaken and completed. Existing and new programs also need to evaluate the services they are delivering so that continuing improvements in services can occur.

In conclusion, the future of end-of-life care and palliative care in Canada depends on our ability to continue to seek answers to important questions pertaining to death and dying. A sustainable, made-in-Canada research program is vital to the continuing development and existence of credible palliative care in this country. Without that, the pace of development will be too slow to keep up with the health care needs of Canada's citizens.

Ms Diane Hupé, Nurse, Vice-President, Palliative Care Program, Sisters of Charity of Ottawa Health Service: I should like to address the issues of coordination and integration, which are very hard to separate from care. I shall address them from three main perspectives, the first being the interface of specialized care with primary care.

From the case study that Ms Bouvette mentioned, which showed an optimal level of care, we see that the oncologist refers the patient to palliative care once no other treatment for recurring disease is provided. The patient has the opportunity to discuss oncology treatment options with his family physician, and the family physician and the primary care team are actively involved in providing ongoing symptom management with the help and support of a palliative consultation team.

The reality, unfortunately, is all too frequently much different. Patients are too often referred to palliative care once the proverbial verdict of "nothing more can be done" is given, and palliative care is seen as a last resort. There is generally a lack of communication between cancer care specialists and family physicians. It is not uncommon for a patient who can no longer benefit from oncology treatment to be returned to their family physician who has not been informed or involved and who must suddenly take over the complex care of a terminally ill patient. It is no wonder that family physicians are often hesitant to assume the care of a terminally ill patient at home. A lack of knowledge, the heavy time commitment, poor support networks and limited remuneration all contribute to that situation.

It has already been said that access to palliative care specialized teams, especially for consultation in the community, is very limited and in many areas, especially rural areas, non-existent.





From the perspective of the interface of specialized care and primary care, the following recommendations are made. First, there should be integration and earlier involvement of palliative care as an essential component of ongoing cancer care. The same should be applicable for other life-threatening illnesses. This speaks to a change of philosophy that palliative care is not just for the last weeks of life. Second, we need recognition of the key role of the family physician and the other members of the primary care team within the whole continuum of care delivery. They are there to provide basic end-of-life care. Third, to help them, the family physician and the primary care team should have access to palliative care specialists whether they are in an urban or a rural area.

The second perspective I should like to raise has to do with access to palliative care no matter in what setting, and that within an integrated delivery system, as your report recommended. In the case of John and his family, palliative care consultation and advice was available through a variety of means -- an ambulatory palliative care clinic, telephone advice, a consultation team providing home consultations, and bereavement follow-up for the family. It seems that John received appropriate primary and specialized palliative care in a timely manner in the setting best suited to meet his needs and those of his family. Care delivery seemed to be well integrated to provide a seamless continuum of care.

What is the reality? Palliative care is not available and not accessible in many settings and in many areas of the country. Some examples include the following. Many acute care hospitals, especially since restructuring, lack the basic funding to maintain core palliative care teams of a nurse and a physician, let alone an interdisciplinary team. In many regions, there are few consultation teams available to do consultation in the home or in long-term care facilities. Again, this is especially critical in rural areas. There is a significant need for community hospice services that can provide visiting volunteers, day programs and respite for families. As a result, there are significant unmet needs for simple pain and symptom control in addition to unaddressed psychosocial, emotional and spiritual needs.

The delivery of the limited palliative care currently available is too often fragmented, poorly coordinated and difficult to access for patients and their families. There have been important contributions by some communities across the country in developing integrated delivery systems in Edmonton, Calgary, Winnipeg, Montreal and Ottawa. However, those are more regional projects than the result of provincial long-term planning initiatives.

From that perspective, we recommend that provincial governments and regions learn from the experience of the few existing integrated models and that they evaluate them. We need policy direction and funding to develop and provide essential palliative care services at a regional level. Furthermore, components of palliative care services must be well coordinated and integrated for optimal delivery within the overall health care system. As well, mechanisms must be developed to facilitate this integration. Examples would be common standards, clinical guidelines, information, access to facilitate the movement of patients, optimal use of technology and standardized assessment tools.

The last point that I should like to raise has to do with community care, including support to the caregiver. In the case of John and his family, the patient received home care services, that is, nursing visits, home support, medication and the supplies and equipment that he needed within the service limits of the home care program in his area. Because of a lack of extra health insurance for additional nursing services as John's condition deteriorated, his wife had to quit her job, thus adding to the already high physical, emotional and financial demands of caring for a dying person at home. That says nothing of the care of the children that must continue and help them cope with their father dying.

In this case, their family physician and primary care nurse are caring for the patient, managing the



symptoms and supporting and teaching the wife in her caregiver role. They are supported by an interdisciplinary team who can do home visits. As the patient's condition deteriorates, and respecting his wish not to die at home, there is a bed readily available in a specialized palliative care unit.

What is the reality? In the last few years, health care has undergone a shift to the community and the wish of the terminally ill to be and even to die at home is well documented in the literature. The delivery of palliative care in the community is seriously impeded by a number of factors. The overall funding is insufficient in home care. The delivery structure is too rigid for the 24-hours-a-day care requirement of a terminally ill patient at home.

Frankly, health care still largely remains focused on hospital care. The scope and availability of home care services varies largely from region to region and from province to province, as you have already heard. The current delivery system does not support continuity of care. To give you an example, rather than a primary care community nurse caring for a patient, as in the case of John, it is common to see numerous nurses from different agencies providing care to the same patient. That is largely due to a serious nursing shortage that is only getting worse. This shortage is certainly worse in the community. As well, there is a rigid system of service allocation, all of which makes for significant fragmentation, real risk of mismanagement of a case and additional burden to a family who must deal with so many service providers.

With the shift to community care, there is the underlying assumption that family will take an active role in providing the care. That is certainly the case for the family of a terminally ill patient. The physical, emotional and financial burden is tremendous on the caregivers. There is very little respite available to support them. Often, there is no insurance coverage for additional services, such as nursing shifts or additional home support services. Finally, as was said earlier, not every family physician feels able and willing to care for a terminally ill patient at home and to make home visits.

From that perspective, we would like to recommend the following. We need a national home care strategy with specific standards, for example, on access, as was mentioned earlier by the honourable senator. We need adequate provincial funding and policy for comprehensive home care services with the flexibility to promote and facilitate continuity and comprehensiveness of care. We need mechanisms -- namely proper remuneration and support systems for the professionals providing community care, especially nurses and family physicians. We need services to support and provide respite to the family and caregivers, such as hospice day programs, respite services, and adequate psychological, social and spiritual support to family, including bereavement follow-up.

There needs to be access to palliative care consultation teams to support the primary care team. As well, there needs to be regional specialized palliative care units for the patients for whom complex symptom management requires hospitalization. Finally, we need a comprehensive evaluation of the cost and benefit of palliative care at home, including indicators of quality of life and burden of care.

I should now like to sum up and capture in a few statements what our team has tried to highlight through the discussion of the story of John and his family, approaching it from the perspective of clinical care and the team, education, research and system integration. The case of John illustrates what should optimally happen in the provision of end-of-life care. If we were to sum up our recommendations into one recommendation, it would be the following: universal and integrated access to palliative care expertise at the end of life for all patients and their families.

Under that, what is truly important, we need a primary care team, especially the family physician, the nurse in the community, the long-term care facility, and other team members, who obtain as part of their





basic training the knowledge, skills and attitude to help them care for terminally ill patients.

We also need to support that team of palliative care experts. We need research and evaluation in order to provide evidence-based and effective quality of life and quality of care. We need those services to be coordinated and integrated, and there is certainly a need for policy direction and appropriate funding, the glue that will bring those services together.

The Chairman: I am not sure I will ask too many questions this afternoon because I agreed with everything you had to say.

[*Translation*]

Senator Pépin: I agree with everything you said. I have followed everything very well, and I think the fact that you presented a clinical case is very helpful to us.

However, there is one thing that aroused my curiosity: When it comes to clinical research, it was said that there were an insufficient number of people dying to allow for a clinical study. How many patients does it take for a nurse or a physician to conduct valid research?

[*English*]

Dr. Viola: My reference to that was not in terms of the number of people dying but access to those patients who are dying by researchers who are trained to do the type of research that needs to be done.

Senator Pépin: So it is the lack of training.

Dr. Viola: Yes, but also access to the place where the people who are dying are being cared for. The dying patients who need to be included in these studies are not always accessible to the researchers who want to do the work. In Ottawa, we are in a special situation. We have a large palliative care unit with 45 beds, which hosts a number of patients of a particular type. We have a cancer centre that we are closely aligned with and can access. We have teaching hospitals. However, across the country that is not always the case. Even in Ottawa, it is difficult, when we want to do the research, to access the specific patients who would really need to be involved in this. It is the access, not the total number.

Senator Pépin: Someone said home delivery care is too rigid. Why is that?

[*Translation*]

Ms Hupé: Take the example of health care in Ontario: We are still following the department's policy which states that there must only be so many hours of nursing care provided, so many hours of visiting homemaker support provided, and this is because the budgets are limited. It is very rigid, and that is where my comment stems from, that there are a lot of conceptual changes to be made when it comes to service delivery, when you are looking at health care in general.

Senator Pépin: Are the hours of care provided to patients being limited in order to ensure eligibility for grants?

Ms Hupé: This is still the case in Ontario, and I think in other provinces as well. If a family has a private insurance plan that is fairly comprehensive, they can use this money to purchase additional services, but it is not every family that has insurance which allows this. Many insurance companies have quite rigid policies and will only provide funds for an authorized nurse, when in fact sometimes all the family or the





patient requires is visiting homemaker support.

Senator Pépin: Are the drugs programs just as inflexible?

Ms Hupé: Each province has a drug plan for home care patients. Nonetheless there are still access problems for some drugs, among others some narcotics with specific dosages that are not covered.

Senator Pépin: Apparently some family physicians are having problems because they are unable to deal with the house calls they need to make when a patient is dying. Is this because they have not received the right training, or because they are not from the generation of physicians who made house calls, or is it that it is just a different approach?

[*English*]

Dr. Schroder: I think it is a combination of things. As a result of the work we have done with our family physicians here in Ottawa, we recognize that some people will never do home visits. It is an attitudinal thing, possibly something that is coming with the new generation of physicians.

Senator Pépin: They want to be paid for that.

Dr. Schroder: Some of it has to do with payment, but it is partly a social thing. Some doctors have decided to have a 9-to-5 practice, which does not include home visits. That is a small portion of the family physicians. Most family physicians genuinely want to do home visits. They have a connection with their patients that is incredible. If they are able to follow a patient at home through the dying process and offer the bereavement help, it is as therapeutic for the physician as it is for the patient and family. However, many of them are frightened because they have not received the training. They get into situations in other settings, do not know what to do, and do not have the support and backup that we can offer here.

Some of it is remuneration. That needs to be examined. This type of care is not just going in and dealing with a physical symptom. It involves a lot of discussion, talking and listening. People have to be remunerated appropriately. There are many issues there.

[*Translation*]

Senator Beaudoin: I would like to get back to the National Health Care Strategy. How can we make this happen? Could it be done by administrative arrangement between Ottawa and the provinces? Would it be possible through meeting with federal and provincial officials? If we want to have a palliative care strategy in this country, then the health ministers will have to come to some understanding and pass an administrative agreement to set it up. I cannot imagine any other way that would work. Both the provincial and federal governments have a major role to play when it comes to health care.

National standards were mentioned, and this is interesting. There is a federal Health Act, that is also interesting, but how will we come up with a strategy? Would it be an agreement between federal and provincial caregivers? What do you foresee? I do not see anything else other than a federal-provincial agreement.

Ms Hupé: The experts who could have answered your questions preceded us. However, I will try to answer your questions. First of all, many terminal patients are at home. This is their wish and this is certainly the way we should be providing health care to them.



Earlier it was mentioned that there were great discrepancies between home care from one province to another. I think it would be important, at the federal level, to establish and recognize that home care services are essential services, in the same way that we do for hospital services. It would be a starting point. And it would provide for basic standards when it comes to access to home care.

Senator Beaudoin: Are you not concerned that a province such as Quebec would say: since health care and home care come under our jurisdiction, give us the funds and we will manage them. This issue must be resolved.

Ms Hupé: Of course under the guidelines that come with the regulations, funding has to be provided, that goes without saying. We need to consider palliative care as a fundamentally integrated part of health care. To this day, palliative care services are still marginal and are not really integrated in the wide spectrum of health care services. I will give an example of a situation that prevails in our region. For a year and a half now, we have been developing, thanks to community and hospital caregivers, an integrated system called the palliative care consortium. In order to help us, we have based it on a small source of funding available through a palliative care association. Lately, the funds have been in real jeopardy.

In our discussions with officials from the Ministry of Health, we learned that one of their biggest problems is the continuity of the funding. The problem is not the direct funding of the care, but rather funding the few positions that coordinate the care. Where should the money come from, to fund this? It is difficult to say. Palliative care does not fit into any of the existing silos -- if I can use the term -- within the Ministry of Health in Ontario. Palliative care services, to this day, are still not considered an essential service needing to be integrated.

[*English*]

Senator Corbin: I agree with you, Madam Chair, this is an excellent brief.

Dr. Schroder made a comment about continuing medical education that attracted my attention. Last week we heard from the Royal College of Physicians and Surgeons of Canada. Following their testimony and some questioning, I was under the impression that they were on the right road with respect to specialization in the field of palliative care. However, Dr. Schroder, you seem to throw a stick in the spokes this afternoon. I know you do not want to be critical of your colleagues generally. Perhaps it is a misunderstanding on my part. However, the impression I get is that what they are doing is fine as an objective, but it will take much more time and resources before there is a real impact on that front.

The Chairman: Before you answer that, it is important for senators to understand that the representatives from the college actually made exactly the same point as the witnesses, that while there are 15 medical schools, I think they said only four specialized facilities are expected to be up and going this year, and even those four at this point did not have funding. Their concern was exactly the same as yours.

Senator Corbin: The objective is laudable, but could you elaborate?

Dr. Schroder: That would not be continuing medical education, really. Continuing medical education is for once one has graduated and is out practising. I would classify this more under specialty post-graduate training. Some of the physicians who would come back and take advantage of the programs may be physicians who have been practising for a while, but some of them may be physicians who are just completing their residency in family medicine or internal medicine or whatever.





I believe there are seven faculties that have expressed interest in that field that will be up and running. However, the biggest stumbling block is funding in terms of those residency slots. Who will pay the salaries? Also, if you look at the guidelines of what is to be offered in training, there is still developing the infrastructure to be able to offer that. Further, the difficulty is that even if they are up and going and there is funding and each of the four faculties is producing two specialists a year, it will still be a long time before we have a critical mass of palliative care specialists.

The University of Ottawa, through the Institute of Palliative Care, has been training specialists for 10 years as a fellowship. They graduate between one and three persons a year, but that is a drop in the bucket. What happens too is, as they graduate, most of those people end up going to larger centres. Who will serve the rural areas? How will we address the far North and the aboriginal population? It is incredible when you begin to think about it.

The unfortunate thing is re-reading the 1995 report and being reminded of the commitment to education. There is a lot of rhetoric here, but there is nothing in practice.

Senator Roche: I hope that the line Ms Bouvette used -- that there is no ideal place to die -- will find its way into our report. I thought it was very appropriate and telling. I suppose that is right. I would add a proviso that, if you are to die, the ideal circumstance is to be surrounded with love and comfort. In my experience, I think that one would not want to say that love and comfort can be found only at home. Circumstances might preclude that. Love and comfort might well be found in a palliative care centre. Thus, as is evident from all the testimony we have heard, there ought to be more facilities. Virtually every witness has made that point.

Ms Bouvette, you said that, at home, the contact with the family physician is lost for a while as the specialists perform in their areas of expertise. When a terminal situation becomes clear, the family physician comes back into the picture. I took from what you said and from your experience as a nurse that there are many problems with family physicians doing home visits and that that is an impediment to dying at home, because you cannot get the doctor there.

Is it really necessary at that stage to have the doctor present? If home care programs were advanced in this country that ensured the proper blend of nursing care, case workers and social workers for the administration of medicine, would the physician actually have to be physically present to write the prescription, so to speak? He or she does not have to be there to administer the prescription.

I am trying to determine whether we might, in our report, enhance understanding of the values of dying at home by calling for stronger support systems for the family that do not necessarily include doctors. That is the first question.

Ms Bouvette: I think what you are referring to is the possible role of the clinical nurse specialist, for example. I do believe, though, that there is a minimum of involvement of a physician that is required. That does not mean it must always be the physician doing the home visit. It could be a nurse specialist. When I do home visits I do not always have a physician with me. As a nurse, I am able to assess, speak to the physician on the phone and make my recommendation over the phone.

I believe it would be wrong to have a patient followed at home by a team without having the physician lay eyes on that patient on a regular basis. That does not need to be frequently. We could create other sets of problems by doing that. My colleagues may wish to add to that.

The Chairman: Is that partly because there is still that knowledge relationship with the physician and the





patient, and the patient really thinks the doctor knows best?

Ms Bouvette: That could be. However, we can build trust, and when we show that we know what we are talking about, certainly that trust can be built. There is no problem.

There is also the fact that, bottom line, a nurse is a nurse and a physician is a physician, even if nurse practitioners are trained to assess well. I hear you loud and clear, and I certainly think there could be a greater role for a nurse specialist to minimize the visits of the physician, be the eyes of the family physician, and assess the patient.

Senator Roche: What I was trying to get at is that I do not believe that the absence of a physician in the home care of terminal cases needs to be an impediment to the person staying at home if the other circumstances are right, if there is enough support care. That is the point I wanted to make.

I want to come back to the question of the relationship of money and education. We are told that the medical schools are only just getting into the training of palliative care specialists, and one of the problems is funding. I think we can perhaps assess the situation by recognizing that society generally has not yet fully understood the value of palliative care. I wonder, though, if the medical profession needs a bit of a boost to push palliative care onto the political process.

I hear the witnesses saying to us, by implication, that our report should be strong in the political process to make the acquisition of funds for this training in palliative care and provision of palliative care a priority. Is it possible that the health care providers themselves have traditionally shied away from this because they go into the training to get themselves ready to be health providers? They want to save lives and see progress. Generally speaking, people do not get involved in palliative care to deal with the dying, they do so in order to promote the living.

I have had a fair amount of non-medical experience with people close to me dying. I sense that the medical profession is uncomfortable with dying, as if it is a failure to cure the person, to make the person well, which is what they really want to accomplish. I think you see my point, that it will not be good enough just for the political processes here to push into the system, although that should be done. The medical profession will need to push much harder -- the medical profession defined as health care providers, physicians, nurses and everyone else -- in order that society get a better understanding of the values of a dying person being protected through love and comfort.

Dr. Schroder: Actually, I can back up a bit and include some of your last question with respect to whether you need a physician if the patient is dying at home. The physician is seen as the person who writes the prescriptions. In fact, that is not the role of physicians. They work as an integral part of a team, and they not only look at the physical issues but they also may be the ones that connect on the psychosocial and spiritual issues. That is why, as a team, it is very important to have all the components. Within the team, then you can decide who does what, and that may be someplace where one can look.

It is true that for physicians the socialization is this cure mentality as we go into training at an undergraduate or post-graduate level. If we cannot cure, then we are failures. As I said earlier, that is part of what we need to be doing in terms of education. We need to start very early on, at the undergraduate stage, and change that to a "care" mentality.

You are right, we could get all kinds of funding for palliative care, but within the faculties of medicine there must be the sense that this is an important part of training. If many of the people who are in the hierarchy themselves are not in that care mentality, then it takes longer. They see this as a question of



how to add it into our current curriculum. We have so much in the undergraduate curriculum and post-graduate curriculum, how do we add palliative care?

That feeds into what Ms Hupé said about the need to be integrated and the need to change attitudes. We need to change that socialization of physicians to understand that it is not a failure if you cannot cure your patient. A failure is to abandon that patient. We can start making inroads there. Attitudinal changes take a great amount of work and effort, and you need to start early on.

However, there is hope. In dealing with the family physicians and some of the specialists here, I see that there is a gradual change. There is the realization that we can always do something more for that patient, even if it is only to sit and listen. As a physician, I might not be able to write more prescriptions, but I can sit and listen in order to validate that person, to journey with that person, whether I am a physician or any other member of the team. That is important to understand and get across to the medical students, to the family practice residents, to the internal medicine residents. We need to start and we need to start now.

Senator Roche: I suppose that is right. Pardon my saying, in a friendly spirit, that I have not met many physicians who will sit down and talk. When I am with them I am so nervous about using up their time when someone else may need it more.

It was said here that palliative care has been treated marginally. We are trying to emphasize the priority for it. I am sure the committee will move in that direction. When the cuts in health budgets that were a famous part of the early and mid-1990s took place, did you find that those government cuts in health care had an adverse impact on palliative care? That is to say, did palliative care take a harder hit in the development of all those services precisely because it was seen as being marginal and not central or taking the operation to a high level?

Ms Hupé: You are right. In many settings, palliative care took quite a hit. Because there was no designated funding for palliative care, much of the time it was up to the goodwill of institutions or other organizations to provide some funding for palliative care. When the cuts came about -- that is, the soft funding -- choices had to be made. Oftentimes, that kind of service was removed because it was something that was not funded globally initially.

Senator Roche: Would you say, Ms Hupé, that palliative care suffered, financially speaking, disproportionately to other aspects of health care as a result of the cuts?

Ms Hupé: What is disproportionate is that there was so little funding. Furthermore, it was so vulnerable to start with that any cuts ended up having a major impact.

The Chairman: While you were giving your testimony today, you reminded me a great deal of my parents. They died seven months apart, from very different things. My father had been a minister of health in a province and doctors were part of his group, if you will. Consequently, he wanted doctors around him. On the other hand, my mother was a nurse, and she did not want anyone but nurses around her. You reminded me of that when you were telling your stories.

Your testimony has been thoughtful and concerned. I think it reflects the concerns that most of us have.

Ms Hupé: We have been very honoured to be part of your discussion.

The Chairman: We have two researchers who will address us now. Both of them deal with end-of-life





research. I want to make that perfectly clear. Neither of them researches euthanasia and assisted suicide, but some of the research they do asks questions involving those areas. However, that is not their focus. Their focus is on the end of life. I wanted to preface my remarks so that if they get into these murky areas, you will understand that that is not where they are coming from but that, yes, some of those questions do have to be asked in order to get the kinds of answers they require to their other research questions.

We will begin with Dr. Harvey Chochinov, from the University of Manitoba.

Dr. Harvey Max Chochinov, Department of Psychiatry, University of Manitoba: Honourable senators, let me begin by expressing my sincere appreciation for the opportunity to speak to you today. It is hard to believe that so much time has passed since I last stood before the Special Senate Committee on Euthanasia and Assisted Suicide. I hope the intervening years have been good ones for each of you. For those of us working in end-of-life care, these years have been marked by significant activity, some frustrations and disappointments, and ongoing challenges.

As you may recall, my testimony in September of 1994 consisted of telling you about a body of research I have been conducting addressing psychiatric issues in the terminally ill. The contents of those studies are salient to the current proceedings, given that many of them have attempted to understand why some dying patients may covet a hastened death. This research update addresses the Senate's prior unanimous recommendation that research into palliative care -- especially pain, symptom relief, and knowing more about patients who might request euthanasia or assisted suicide -- be expanded and improved. I also thought it important for this committee to see an example of how palliative care research actually looks, so that they can see firsthand how work of this kind can increase our understanding and provide better care for the dying.

By way of a brief review, in September of 1994, I told this committee about a study our group at the University of Manitoba had conducted involving 130 terminally ill cancer patients all receiving in-patient palliative care. That was one of the first and certainly largest studies to look at the epidemiology of depressive illness in the terminally ill. We reported in the *American Journal of Psychiatry* that, depending on the way the psychiatric diagnosis system was applied, anywhere between 13 per cent to 26 per cent of patients nearing death had a major depression or depressive syndrome. The committee may also recall that I spoke about a study involving 200 dying patients, all of whom were asked if they ever wished that their illness would progress more rapidly so that their suffering might be over sooner. From that study we learned that 55 per cent of patients nearing death endorsed no desire for early death. However, nearly 10 per cent endorsed a moderate or genuine desire for death to come early.

We went on to compare patients with and without a desire for death and we found that the prevalence of clinical depression in those who desired death was over 60 per cent, compared to about 7 per cent in those who did not covet a hastened death. We also found that the prevalence of pain that was of moderate severity or greater was nearly 80 per cent. We reported that patients with a desire for death experienced their families as less supportive compared to patients not reporting a genuine desire for death.

In 1995, Dr. Keith Wilson and I published a model in the *Canadian Journal of Psychiatry* that looked at the connections between pain, family support, depression, and a desire for death. This model indicates that while pain and family support are important variables, depression is the most important predictor of patients who may covet a hastened death. Thus, while physical symptom distress and social considerations are critical, understanding the psychology underpinning a patient's desire for death





appears to be particularly significant.

If clinical depression is present in one to two of every 10 dying patients, it is important to note that fewer than 5 per cent of patients appear to receive any treatment for depression. As such, we published a study that examined several brief screening approaches to help clinicians identify depression among patients nearing death. This slide demonstrates the different screen approaches we utilized in this protocol. It is most interesting that with a single-item screen that essentially consisted of asking patients if they were depressed most of the time, we were able to identify every patient in a cohort of 200 dying patients who was suffering from depression without misidentifying any patient. Thus, we indicate on this slide that the sensitivity and specificity of that screening approach is 100 per cent.

That screening approach was recently cited in a paper published in the February 1 issue of the *Annals of Internal Medicine* that summarized a consensus panel of the American College of Physicians/American Society of Internal Medicine on end-of-life care. It is our hope that endorsements of that kind will see clinicians more readily identify patients whose suffering, at least in part, may be explainable on the basis of an underlying depressive illness.

Our group is also trying to examine the extent to which dying patients are aware of or able to acknowledge their terminal prognosis. Insight into illness was measured on a three-point scale: those who had no insight, those who believed that their illness was curable, and those who had good insight or full understanding of the gravity of their illness and the imminence of death. As you might expect, we found that most patients were able to acknowledge complete insight, although about 10 per cent denied their terminal prognosis and foreshortened life expectancy. Perhaps most significant, however, is the fact that those who were unable to acknowledge their terminal prognosis and imminent death were also three times more likely to be suffering from depressive illness.

Over the last five years, my colleagues and I have also been trying to study and follow closely the fluctuations that can take place in the will to live among dying patients. Twice daily, patients were asked to indicate on a scale of zero to 100 their intensity of endorsement for various different symptoms, including their current will-to-live intensity.

Here are the will-to-live fluctuations in an 80-year-old woman with colorectal cancer. Notice that when she first entered the hospital her scores were quite high, indicating the paucity of will to live. That is the data indicated on the left of the slide. After several days of being in hospital, her will to live scores improved until she was very near death, at which time her will to live became very highly fluctuant or unstable.

I have shown the will to live pattern of the same patient along with the temporal changes in her reported pain intensity ratings. The story that slide tells is quite profound. It demonstrates a marked relationship between pain and will to live. This particular example is reported as part of a paper we recently published on will to live in the terminally ill in the September issue of the British journal *The Lancet*. Nearly 170 patients participated in that study.

This slide indicates that within a 12-hour time frame, the average maximum changes in will to live varied by as much as 30 per cent to 40 per cent. By the time we looked at maximum average changes occurring in a 30-day time interval, fluctuations ranged from 50 per cent to 80 per cent.

If, as it appears, will to live is something that can change quickly over the course of one's dying, why might that occur? We found that within the first 12 hours to 24 hours of coming into a palliative care ward, a time of transition for most patients, the anxiety rating seemed to predict the largest changes



taking place in patients' ratings of will to live. By the time we had followed patients for one to two weeks, depression seemed to be the most significant factor in predicting fluctuation in patient ratings of will to live. Finally, as death was drawing nearer as we followed patients into the third and fourth week of the study, physical symptoms of distress, especially shortness of breath, seemed to account for most of the fluctuations in will-to-live ratings. This provides an empirically based model to help clinicians understand the changing landscape of will to live among patients nearing death.

Recently, my colleague Dr. Douglas Tataryn has been taking the lead on a series of further analyses on a will-to-live data set. As you can see, we have found that some patients are able to maintain a relatively consistent high endorsement of their wish to go on living. Conversely, there are others who maintain a significantly poor or low endorsement of their wish to go on living, thus the high scores on that will-to-live visual analog scale. Three other discernible groups were also noted, including those who sustain a moderate wish to go on living, those who appeared to increase their endorsement of will to live as death approaches, and those who seem to relinquish the will to live as death draws nearer.

The will-to-live maintainers accounted for about 57 per cent and thus represent by far the largest majority of patients in our study. It would thus appear that most people we studied came into hospital with and in fact maintained a high endorsement of the wish to go on living in spite of their terminal circumstances. Eighteen per cent seemed to lose the wish to go on living as death drew nearer. Twelve per cent of patients seemed to sustain a moderate wish to go on living throughout their course, while a small group seemed to actually acquire the will to live toward the end. Finally, the smallest group, but certainly among the most interesting, consisted of those patients who established a lack of will to live.

It appears that there was a disproportionately high prevalence of colon cancer in patients who gained or acquired the will to live and, as you might have predicted, nausea was also highest in this group. Nausea is a particularly treatable symptom in a setting of palliative care, and this may be indirect evidence that treating distressing symptoms, such as, in this instance, nausea, may help dying patients reacquire their waning will to live.

We also found that the group of patients with a sustained lack of will to live was the least likely to be married. In fact, none of those patients with a sustained lack of will to live was married, compared to at least 50 per cent in all other categories. It is also notable that patients with a sustained lack of will to live reported the highest levels of anxiety and the highest levels of shortness of breath. Thus, the evidence would appear to suggest that patients with a sustained lack of will to live may be more isolated and particularly symptomatic. It is also interesting that those with a sustained lack of will to live died soonest.

With funding from the National Cancer Institute of Canada, our group has also been studying the issue of dignity among the dying. Loss of dignity has been cited in several studies as the most likely reason physicians ceded to a patient request for physician-assisted suicide or euthanasia. In fact, it is not uncommon for people on either side of the euthanasia debate to invoke considerations of dignity as lying at the heart of their respective positions. In a study that has thus far evaluated over 170 patients in several palliative care settings, we are attempting to find out how patients define death with dignity and what factors support or undermine their personal sense of dignity. This study should be completed over the course of the next year and will hopefully provide guidance on how to provide better palliation that is sensitive to the dignity of dying patients and their families.

Finally, I will tell you about an exciting study conducted by my friend and colleague Dr. Keith Wilson here in Ottawa at the Institute of Rehabilitation and Development. This study examined 70 patients





receiving palliative care whose mean survival was 44 days from the time of study entry to the time of death. Patients were asked about their attitudes toward euthanasia and physician-assisted suicide. Sixty-four per cent of the sample endorsed legalization of euthanasia and physician-assisted suicide while 58 per cent could imagine it for themselves under particular circumstances at some future point in time should they suffer from uncontrolled pain, severe physical symptoms, a diminished quality of life, or find themselves a burden to others.

Of the 70 patients studied, 12 per cent would have requested a hastened death at the time of the interview if it were in fact legally available. Their reasons for coming to this decision included complaints of drowsiness, weakness, a sense of loss of control and loss of interest, hopelessness, and a desire to die. Of interest, nearly 63 per cent of patients with an interest in hastened death had a major depressive disorder compared to only 16 per cent of patients who did not express an interest in physician-assisted suicide and 21.9 per cent of patients who expressed only a possible future interest.

Let me go back to the question of what progress has been made in palliative care research from a national perspective in the last five years. While there have been some pockets of success by way of individual operating grants and a few critical publications, palliative care research on a national basis has made little headway. We have lost some of our most distinguished palliative care researchers and still have not managed to launch a national palliative care research strategy. A Canadian palliative care research initiative, which had generated significant private-sector interest, failed to attain federal funding.

A Health Canada project to develop a Canadian agenda for research in palliative care employed a three-part national consultation service. Amongst their findings were the following: The existing Canadian research infrastructure is currently inadequate to insure the timely production of useful knowledge related to end-of-life care. New research needs to be developed and supported so that they can take their ideas and research activities into the future, enabling advances that will improve the experience of dying Canadians. Failure to move forward on a national palliative care agenda will result in needless suffering well into the next millennium for dying patients and their families.

I have tried to demonstrate that end-of-life care issues, even the most seemingly difficult of issues, can be studied and addressed in an objective fashion. Palliative care research on a broad range of issues is desperately needed if we are to avoid care that is guided either by ignorance or desperation. Quality end-of-life care research provides the knowledge upon which clinicians can base their decision making, enabling palliative interventions that are sensitive to the needs of dying patients and their families.

Let me offer five specific recommendations for your consideration.

First, the Senate committee's frame of reference is essentially end-of-life care. The title of its final report ought to be "The Senate Report on End-of-Life Care in Canada." A slightly more provocative title to consider would be "End-of-Life Care: A Crisis in Canadian Health Care." Either title will avoid the possibility that the thrust of this report be misconstrued to have a euthanasia or assisted-suicide focus.

Second, that this committee advocate for designated funding, perhaps within the CIHR, to serve as an incentive for training and palliative care service delivery and especially to support end-of-life care research.

Third, that all medical training facilities and licensing agencies be required to include the demonstration of competence in end-of-life care as a condition of their awarding certification or licensure.





Fourth, that all health care facilities, including hospitals and long-term care facilities, be required to demonstrate appropriate standards and competence in end-of-life care including regular monitoring, with appropriate outcome measures to assure quality assurance, as a condition of accreditation or the maintenance of their operating licence.

Fifth, that the federal government and Health Canada be held accountable to the Senate recommendations by way of having to produce an annual report on the status of and progress made in end-of-life care nationally.

I believe that these recommendations would go a long way towards achieving the ultimate goal -- that is, seeing all Canadians having access to excellent, comprehensive end-of-life care in their time of need.

Senator Corbin: On a point of order, we did not get the text of the recommendations that the witness just read. I wonder if copies could be made now for distribution.

Senator Beaudoin: Do you want the report to be labelled?

The Chairman: We will get all of those recommendations and then we will put questions to Dr. Chochinov.

However, we will hear from Dr. Singer first.

Dr. Peter Singer, University of Toronto: Honourable senators, each year approximately 222,000 Canadians die. What is the quality of end-of-life care received by these fellow citizens? We simply do not know.

I regret to report that when I speak to groups of health care providers or the public they usually rate their perception of the quality of end-of-life care in Canada as a "C" on a school report card of "A", "B", "C", "D", "E" and "F". This is not an acceptable grade for cardiac surgery, and it should not be acceptable for quality end-of-life care. We need to take a fresh look in this country at how we care for dying Canadians, and we need to take active steps on how to improve on this care.

Your report "Of Life and Death" made a significant contribution. It clarified the distinction between euthanasia and assisted suicide on the one hand and a spectrum of practices, including palliative care, pain control and sedation, withholding and withdrawal of life-sustaining treatment, and advance directives on the other hand. This is a critical distinction, which needs even more reinforcement and public discussions about dying. When you pick up a newspaper, listen to the radio, or watch a television show, if the topic is about end of life, nine times out of ten the specific issue or the case will involve euthanasia and assisted suicide. However, at the bedside of these 222,000 Canadians who die, 99 times out of 100 the issue is not euthanasia or assisted suicide but rather those other practices that you talked about in your report -- palliative care, pain control and sedation, withholding and withdrawal of life-sustaining treatment, advance directives, and so on.

I take no position on whether or not we should legalize euthanasia or assisted suicide. I am quite sure, however, that if we legalized it tomorrow, it would have a negligible effect on improving the quality end-of-life care of those 222,000 Canadians who die each year.

Let me now focus on the recommendations in your 1995 report, "Of Life and Death," dealing with palliative care, pain control and sedation, withholding and withdrawing, and advance directives. In your report, you addressed these issues thoroughly and effectively, but separately. I think the main step you



should now take in updating your report is to bring these issues together into a single integrated concept -- quality end-of-life care -- and focus on how quality end-of-life care received by the 222,000 Canadians who die each year can be improved.

What is quality end-of-life care? Several expert groups, including the U.S. Institute of Medicine, have tried to answer that question. My colleagues and I, including Douglas Martin, from whom you will hear tomorrow on the topic of advance directives, decided that the limitation of these approaches was that they all came from the expert perspective. We conducted a research study to ask patients themselves what quality end-of-life meant to them, and they told us that it included three domains: Adequate pain and symptom control, appropriate use of life-sustaining treatments, and support of patients and families. These domains incorporate the varied issues you addressed in your 1995 report, and now there is a research basis for pulling them together into an overarching concept of quality end-of-life care.

We are now at the point where we recognize that 222,000 Canadians die each year, that most people think that the quality end-of-life care they get gets about a "C" on average -- there are pockets of excellence, to be sure, but, on average, a "C" -- and where we have a unified focus defined by patients themselves that can serve as a target for quality improvement. The question now is how to improve the quality of end-of-life care that those 222,000 patients receive. Let us think about that at three levels: clinical, organizational, and health system.

At the clinical level first, this has been the major but by no means the exclusive contribution of the palliative care movement over the last 10 to 20 years. In addition to the specialized expertise of palliative care providers, we need all front-line health workers who care for dying patients to have skills in providing quality end-of-life care.

I am an example. I am a practising general internist in a hospital. Approximately 10 per cent of the patients admitted to a ward like mine die. I am not a palliative care specialist. It is front-line health care workers like me that we need to target in our health care initiatives.

The University of Toronto has recently launched the Ian Anderson program on end-of-life care based on a \$1 million donation from Mrs. Margaret Anderson that aims to train 10,000 physicians in Canada in end-of-life care over the next five years. The press release for this is at the back of your package, and I will come back to this in my recommendations. Here is a situation not where I am suggesting that we need more funding; we have the funding. It addresses many of the issues you have been talking about in the last several hours. The question becomes: How can we work together to put it to the most effective use?

Second, let us focus for a moment at the organizational level. During the past five years, quality end-of-life care has become an issue in institutional accountability. Quality improvement methods have been used to improve end-of-life care, and there are very exciting possibilities here, including report cards for hospitals on quality end-of-life care, viewed as an issue in institutional accountability.

I explore many of these strategies and ideas in a paper that I have deposited with the committee clerk. We can return to those during the question period if you like. The general concept is that a quality assurance mechanism exists in health care. It is not often applied to the area of end-of-life care, but it can be, with some innovation. That can lead to wonderful improvements in organizational accountability.

The third level I want to address is the health system. The first level is not an innovation, it has been there for 20 years. How can we improve education and improve our efforts at the clinical level? The second level has been there for about five years. Organizations realize that this is an issue of





accountability. I believe the health system level, linked to the idea of quality end-of-life care, is an innovation. I shall present a vision for the future quality end-of-life care, as a population health systems issue.

If you assume that each death and the quality of end-of-life care received profoundly affect the well-being of, on average, five other people, members of the dying person's family, then about 5 per cent of the Canadian population is affected by this issue each year. That is a huge number, much larger than many of the diseases that we think about. We do not think about it in this way for reasons you were discussing earlier; however, it is an important population health issue. Quality end-of-life care should be a measure of health system performance, given its importance.

There should be indicators in reports from the Canadian Institute for Health Information, as well as Maclean's reports based on them, about the health system performance in the domain of quality end-of-life care.

In a conversation with the chief executive officer of CIHI, I asked: "What would you say if I told you there was a quality issue that affects 5 per cent of the population every year and that that issue is not addressed in any of your quality indicators?" He replied that he would be interested. It is this kind of innovative work that needs to be done at that level.

In addition, there should be cross-national comparisons in the World Health Organization's world health report in consideration of the 54 million deaths annually, 46 million of which occur in low- and middle-income countries.

Let me now turn to what the Senate of Canada could do to improve the quality end-of-life care received by 222,000 fellow citizens who die each year.

First, when you update your report, include a chapter entry on quality end-of-life care, drawing together the previous chapters and focusing on how quality end-of-life care can be improved at the clinical, organizational, and health systems level. Second, at the clinical level, partner with us in the national University of Toronto Anderson program, aimed at educating 10,000 physicians across the country. As part of this program, we hope to hold five transformative conferences targeted at specific sectors. One of the sectors we would like to target is the government. We should do that in partnership.

Third, at the organizational level, we should encourage the Canadian Health Care Association or the Canadian Long Term Care Association, or the organizations that set standards for health facilities, to develop programs for organizational quality improvement initiatives for end-of-life care.

Fourth, at the health systems level, we should encourage the Canadian Institute for Health Information to develop population-based indicators of quality end-of-life care and through Health Canada encourage the WHO to incorporate these indicators in the cross-national comparisons of its world health report.

Since the foregoing recommendations require development of indicators of quality end-of-life care and strategies to use the information to improve end-of-life care, we should support the establishment of Canadian institutes for health research, CIHR, and encourage CIHR to fund the necessary research to accomplish this vision.

Honourable senators, I have presented you today with a fresh and innovative vision on how we can improve Canada's clinical, organizational, and health systems performance in quality end-of-life care. The ideas I have presented build on the fine work you have done in your 1995 report "Of Life and





Death." Both in the context of your work in this subcommittee and in your future work in the Social Affairs Committee studying the Canadian health care system, you can have an important effect on improving how 222,000 Canadians die each year. Our collective vision ought to be the provision of A-grade quality end-of-life care to these 222,000 fellow citizens and their families.

Madam Chairman, thank you very much. I look forward to your questions.

Senator Beaudoin: Dr. Chochinov, you have suggested the title, "The End-of-Life Care in Canada," and, more provocatively, "The End-of-Life Care: A Crisis in Canadian Health Care."

In my opinion, the word "crisis" is a bit strong. I say that because it is a controversy but not a crisis, and because, unfortunately, we will all die. What would be the perfect French translation of that? I am not too sure. It is very vague, in my opinion. How would it be translated in French?

Dr. Chochinov: I do not know. When I was thinking of the alternative title, I was torn between having the subtitle be "A Crisis in Canadian Health Care" versus "A Tragedy in Canadian Health Care." You point out that, perhaps, it is neither a crisis nor a tragedy because we will all die. It is for that very reason that it is a crisis or a tragedy.

The fact is that all of us will die, yet we know that only a minority of us will have access to comprehensive and excellent end-of-life care. We also know that the quality of that care can only be as good as the knowledge base that underpins it. For those reasons, if access, education, and research is inadequate, it is indeed a crisis and/or a tragedy.

Senator Beaudoin: We are updating a report in the areas in which we were unanimous. How can we object to that? Of course, it is the thing to be done. We should have done it before, and I agree with that. Why change the title?

Dr. Chochinov: There is a good and specific reason for changing the title. I have been reading much of the testimony. I know that there is some anxiety both among some of the senators and the people who have been giving testimony that the thrust of this committee may be misinterpreted or misconstrued as being yet again about the contentious issue of euthanasia and assisted suicide. One of the senators commented previously that, perhaps, the reason that this report did not receive the attention it deserved is that euthanasia and assisted suicide is too hot a political issue and the committee itself was divided. That gave the government as good an excuse as any not to take action.

If we are talking about the unanimous recommendations, we are really talking end-of-life care. Why not call it what it is? Rather than calling it by the previous title, which did address euthanasia and assisted suicide, retitle it so that we know clearly that this is about end-of-life care. Perhaps that will create more of an impetus for the government to take action.

Senator Beaudoin: It is so general that it seems to include everything.

Senator Carstairs: I do not think we should get hung up by this suggestion concerning the title. I suspect it may not translate well into French, at any rate; therefore, we may have to do something entirely different with it. The focus of what Dr. Chochinov is saying -- it is clear and it has come from all of us -- is that we really want to focus on the issues of how Canadians are dying, however we want to title that some time in the future.

Just to refresh the memories of our witnesses and senators, it was never the intention of the committee to



study anything other than euthanasia and assisted suicide. It was only when all these other issues came forward in our debate on euthanasia and assisted suicide that we found ourselves in a real dilemma. We felt it was only fair to report all those things because that is what Canadians seemed to be far more concerned about, quite frankly, than the issue of euthanasia and assisted suicide. They were concerned about palliative care, advanced directives, the withholding and withdrawing of life-support treatment, and adequate pain medication. That is how the report came out.

I agree that we may have to re-jig this whole thrust so that people understand what it is we have truly studied in this update of the report.

Senator Beaudoin: The title of a book or a report is very important.

Dr. Chochinov: Because the initial mandate of this committee was to look at euthanasia and assisted suicide, it behooves the committee to come up with a different title, if the thrust of what we are trying to do is, indeed, different.

Senator Beaudoin: As I have said on a number of occasions, I have no problem with anything on which we were unanimous. As to the rest of it, I am ready to discuss that one day, but not today.

Senator Corbin: In his third recommendation, Dr. Singer speaks of transformative conferences. Pardon me, but my culture does not understand what that means. I have not been involved in any such exercise. I think I understand how it would function, but I should like to add also that one of these should be aimed at government. We here are not government. We are parliamentarians. We may be looked at as critics or advisers to the government, but we are not the government. Perhaps you may want to have a transformative conference with parliamentarians generally, and then another one with governments, which might bring them head on into a clash because things are not working right now. Please tell me all about transformative conferences.

Dr. Singer: It is simply the issue that was being spoken about before in the earlier testimony. There are a number of skills that you want to build. However, fundamentally, part of the issue here is people's attitudes toward death. That is a very, very deep cultural phenomenon, which leads in very interesting ways.

Let us return to the discussion we just had, in order to get parliamentarians on the track that you are on, senator. Let us put aside the issue of euthanasia and assisted suicide for a moment, not on any other grounds other than, perhaps, effectiveness, and let us step back and think about our goal as being those 220,000 people. That is an example of a different way of thinking about things in the parliamentary sector.

I alluded to what the media is doing. The media is another sector that we want to target. As long as 9 out of 10 stories on end-of-life care on television, radio and in the newspapers have to do with euthanasia and assisted suicide, it will be hard to support and sustain an agenda that will really improve the care on the bread and butter issues that affect dying people. Another sector is physicians. Another is the organizations that can promote the ideas that we are talking about at that level.

In summary, what we have in mind in response to your question, senator, is that rather than large continuing-education conferences, where the emphasis is on getting 500 people and teaching them something, we want to target, in each of these conferences, key decision-makers and take them out of the box. We want to introduce different ways of thinking about these things. Frankly, it is to break the deadlock that has stifled innovation and improvement in end-of-life care, some of the issues that we





were talking about. By transformative conferences, we are trying to strike the issue of attitude and conceptualization of the problem. I have presented a very different conceptualization of the problem from other versions that you may have heard.

Let us change the thinking of critical people -- editorial boards of newspapers, parliamentarians, and so on -- about this issue to complement these 10,000 physicians or health care workers who will be out there with improved skills.

The Chairman: How will you train 10,000 physicians for \$1 million? That is only \$100 per physician.

Dr. Singer: That is a very good question, and one with which we have struggled. We started with 12,000 and I bargained them down to 10,000.

We plan to use a distributive model. Even though the donation was to the University of Toronto, we plan to build a national partnership of health educators across the country, like the people you heard from before. You heard them say that their problem was funding for their educational programs, et cetera. We want to bring together people geographically as well as by specialty, develop the curricular materials, locate the educational influentials and serve as, if you will, a clearing house to keep track of these physicians. It is a distributive model of education and very consistent with cutting-edge principles of continuing education.

None of us will do the front-line work. We will join in partnership with our colleagues across the country to do this. This system is already in place in continuing education through the colleges. Recently, the colleges have required continuing education on the part of health care workers, both family physicians and specialists. We want to target some of those requirements to end-of-life care. If we were going to do it along a conferencing format and had a vision that we would do it ourselves, there is absolutely no way that we could do it. However, if we can use this \$1 million to leverage work with our many dedicated colleagues across the country and work with the colleges and so on, then we can do it. Moreover, it is based on cutting-edge principles of continuing education, which say do not go show someone a lecture but give them the materials and set up the interactive groups of 10 physicians across the country. We want to provide the educational infrastructure for that, not necessarily employ the teachers to do it because there are already dedicated teachers with the skills to do it, as you have heard from many others in other testimony.

It is a challenge. We want to make this a transformative program. We know from continuing education research that you have to get a particular proportion of the whole workforce -- 57,000 physicians in the country -- to achieve a transformative and sustainable change. That is why we aimed at 10,000.

The Chairman: Even if you just get them all talking about it, it will be a positive achievement.

Dr. Singer: No, not at all. What you must realize is that we are talking about something different from training specialists. Let me take a step back.

Some 220,000 Canadians die in the country each year. About one quarter of them die from cancer; three quarters die from something else. Palliative care services are primarily targeted in the cancer model. They are dealing with one quarter of the people who die. I am not arguing they should be, I am just arguing that that is often how they are set up for historical reasons. Of the one quarter of the people who die of cancer, generously, let us say, one half have access to palliative care expertise. You are looking at an overall penetration rate of 12.5 per cent in terms of access to specialized palliative care services. You ought to fund more, and you ought to recommend funding more.





The fact is that most of those people who die will be treated by people like me. We want to bring up the level of skills of people like me one notch. Thus, it is not an in-depth two-year training of a specialist. It is 10 to 12 hours targeted on critical cases and critical issues in the right educational format on the part of 10,000 people and then setting them up in a network where they can continue to learn from each other. Using e-mail list serves, Web sites and so on will have a great effect on how the other proportion of people who die in the country receive their care because they receive that care from people like me.

The Chairman: Dr. Chochinov, you have been engaged in five to eight years of research relating the effects of depression on attitudes of people who are dying. I know that you have contact with all of the physicians and with the palliative care centres in our hometown of Winnipeg. Are they now treating for depression?

Dr. Chochinov: Depression is now being recognized as a clinical entity that accounts for some suffering that we see among the dying.

There was a recent survey of psychopharmaceutical intervention in patients at the end of life, and the prevalence rates of patients who are receiving treatment is still lower than prevalence rates of depression appeared to be, so we are only making initial headway.

The paper that I cited from the Annals of Internal Medicine is another example of how research can heighten sensitivity on the part of care providers to being able to recognize depression.

Many of the studies that have been done thus far have looked at trying to determine what is the extent of the problem. What is lacking in the area of research, and what very much needs to be moved into, is the whole area of interventional research. At this point in time, there are no randomized, controlled trials of anti-depressants among the terminally ill. There are a few smaller trials that have shown them to be efficacious, but a good, randomized, controlled trial is yet to be done. We still have a long way to go in doing the proper intervention trials.

That is probably true in palliative care in general. The focus in the literature has been to try to define the scope of the problem, whether in terms of symptom management or the extent of existential suffering, and so on. What is lacking is research into the domain of interventions.

The Chairman: Senator Roche was not there, but Senator Corbin, Senator Beaudoin and myself were in Winnipeg when Dr. Chochinov first presented in September 1995. I had just joined the committee. When he came with his, at that point, preliminary research data, my immediate reaction was: "Of course they are depressed. They are dying." It seemed quite an obvious statement. However, what you are now telling us now is that it is still not obvious to a lot of people that these people might be depressed.

Dr. Chochinov: The fact is that it is a significant minority of patients who suffer from depressive syndrome. We make the distinction between clinical depression, or depressive syndrome, and the kind of sadness that all of us, of course, experience in the face of life's adversities.

Senator Roche: Dr. Chochinov, you made it clear that you want the committee to concentrate on palliative care and to get off assisted suicide and euthanasia. I thought your presentation was fascinating, and I congratulate you for it, but it was a little fast so I am having trouble recalling precisely what you said. If I am not mistaken, you did introduce euthanasia and assisted suicide. I would ask you to take me through it again. Does the knowledge that you are going to die, and a subsequent depression over it, increase the desire for assisted suicide or euthanasia, or did I get that wrong?



Dr. Chochinov: There is an association between clinical depression and those who would disavow their prognosis. There is also a very direct correlation between those who are clinically depressed and those who may desire a hastened death. One of the studies that I presented indicated that, if you are in that group of patients who have a genuine desire or express a genuine desire for life to be over sooner, the chance of your being depressed is probably 10 to 12 times greater than if you do not have a desire for death.

Senator Roche: If one has a desire for death, it does not mean that that person is seeking assisted suicide or euthanasia.

Dr. Chochinov: That is correct. Senators may be interested in an article in this week's issue of the New England Journal of Medicine. There are three interesting studies that you may wish to look at. One of them looked at complication rates in assisted suicide and euthanasia in Holland and found that the complication rate is in the order of about 20 per cent. The other two studies, which are particularly important, report on the experience in Oregon following passage of their Death with Dignity Act. As senators know, that act passed with a 60 per cent majority. In other words, of every 10,000 Oregonians, 6,000 indicated that the Death with Dignity Act -- assisted suicide -- would be good social policy. The articles in this week's New England Journal of Medicine said that, of those 10,000 Oregonians, if you now move them forward to time of their death, only 60 actually made a request for a lethal prescription. Of those 60, only 10 were deemed to fall within the guidelines of the Death with Dignity Act, and of those 10, five, in fact, died of a lethal overdose. While 60 per cent of Oregonians may support this as good social policy, only one half of a tenth of a per cent actually availed themselves of that policy.

Senator Roche: That is very interesting, and I hope the research staff will look at the material that has been referred to.

I will try to sharpen the question. I did not quite get it out a minute ago. Just because you have a desire for death, it does not mean that you are seeking assisted suicide and euthanasia, and you have confirmed that, but it might.

What I am concerned about here is the public perception and, again, the governmental response.

I know, Senator Carstairs, we are probably going to have this discussion later on when we consider the manner in which the report is going to touch on this subject. Just because we are dealing with palliative care and all the questions associated with palliative care in this study, which I endorse, I have yet to quite understand how we are going to separate ourselves totally from euthanasia and assisted suicide questions that are in the public mind and with which so much of the public identifies palliative care. Maybe I just have not finished sorting it all out in my own head, but I will try the following question on you.

I put it to you that it is impossible to totally separate these questions. Just because we want to deal in this report with palliative care questions, the evidence you have given leads me to believe that I do not see how we can ignore saying something about it, even making the point that palliative care is not assisted suicide. However, when you get to the desire for death, how can we avoid dealing with the question?

Dr. Chochinov: I think you do so just by saying upfront that you are not going to deal with the questions of changing social policy and that you are going to understand desire for death as being one of those indicators of suffering among patients who are nearing death.

Senator Roche: You mean we should go upfront in our report?





Dr. Chochinov: Absolutely. After you have changed the title, the preface would stipulate that although there are many social policy issues to be considered that is not the focus of this study. This study will broach issues like euthanasia, assisted suicide, and desire for death, and will understand those issues as expressions of suffering among the dying.

Senator Roche: I put it to you that the more people understand the virtues and values of good palliative care, the less public desire there will be for assisted suicide.

Senator Beaudoin: That is what I think.

The Chairman: I do not think that either of the witnesses would disagree with that. Dr. Chochinov, let us say that we are writing the report and want to make a reference to some of the research that you have done. Would you be content with a comment to the effect that your research would indicate that one of the issues that must be dealt with in good palliative care is the issue of depression among patients at the end of their life?

Dr. Chochinov: Absolutely, but I think that you need to go broader than that and talk about the whole area of symptom control and symptom management. However, in terms of depression, it absolutely needs to be included.

Senator Corbin: In terms of the research, is near-death depression a particularity of western culture? Let me expand. I have had discussions with persons of other cultures and, from what I have heard, it seems to be that depression is not for them necessarily an end-of-life issue or problem at all.

Has your research been cross-cultural, or have you targeted one group of persons to the exclusion of others? How do you resolve issues such as these, because Canada is very much a multicultural, multi-religious, multi-ethnic country. What credibility can I give your research if I place it in that context?

Dr. Chochinov: Each time I present my research, someone will always ask me: Have you taken this or that fact into account? The answer is that the research is limited. There are only so many factors that can be taken into account, both because of the limitation of the researchers to anticipate them all and because of the expertise of the researchers to incorporate all of those things into a palliative care protocol.

Also, this is a difficult population to study. If you start to include issues such as culture, ethnicity and religion, it expands the length and, thus, the burden of the protocol that is being administered to patients.

Most of the research we have done has taken place in one of Winnipeg's two in-patient palliative care facilities. There is a broad spectrum of cultures represented within those communities, but, again, primarily an older, cancer population.

Earlier on I was asked why we primarily studied cancer patients. The reality is that the majority of patients who enter palliative care facilities have cancer.

Your comments are well taken, in that we cannot necessarily generalize to all ages, cultures and groups. Nevertheless, it is my hope that they shed some light on an area that has essentially lived in darkness for much of the time.

Senator Beaudoin: In the report, we have made a lexicon. I believe it is very well done, but I am open for discussion if there is a mistake. I do not see one at this moment. However, I never close the door; I like





discussion.

In my opinion, and this is where there is a problem in this country and all over the world, people disagree on some definitions. Some people do not even see a difference between refusal of treatment and euthanasia. I disagree strongly with them. However, I am ready to hear them.

The title of the lexicon looks very vague, but I agree with Madam Chair -- let us for get about it and we will deal with that in due course.

I congratulated those who moved for the formation of this committee because of their foresight. However, it seems that people do not want to follow through on the issues to which we had previously agreed. In all areas on which we agreed, palliative care, withdrawal of services, and so forth, why do we not proceed?

The title of this report would be very easy to find, but I do not want to freeze everything right at the beginning. However, we must convert people and assure them that there are some distinctions. Philosophy in law is the basis of this subject matter. However, we need a definition. We need a lexicon. We need to discuss the issue.

At the end, we agree or disagree. It will always be like that on this beautiful planet. Do you agree that this is what we should do?

Dr. Singer: Yes, I do agree. However, I wish to push that further. You might consider making three moves in your report. First, I would address the issue of euthanasia and assisted suicide versus the other matters. When you say, people confuse it, really what they are saying is that they think it should be legal or illegal, and you want to put that aside up front.

There are, by the way, some things you can point to, like guidelines from the Chief Coroner's Office of Ontario, that clearly distinguish at the level of action, analgesia and sedation, which is palliative care, on the one hand from euthanasia and assisted suicide on the other.

Your second move is to take together these disparate ideas -- palliative care, advanced directives, life-sustaining treatment -- and put them into a unifying process upon which people can focus. I spent five years of my life studying advanced directives before I figured out they were a little piece of the puzzle, an important piece of the puzzle; but that little piece of paper would not do the trick. I stepped back in order to determine the conceptual nub of this problem. You may wish to consider pulling these things together as an issue of quality end-of-life care.

The third step you ought to consider is not just increasing understanding, but thinking about some concrete strategies for improvement.

Senator Beaudoin: Improvement of what?

Dr. Singer: Improvement of quality end-of-life care.

Senator Beaudoin: Nobody wants to die.

Dr. Singer: No, but what they particularly do not want, senator, is to die in pain, short of breath, hooked up to a machine, alone. Nobody wants to die, but what they especially do not want is that public vision. That is why most people say that quality end-of-life care in Canada rates about a "C".



You can still have the same 222,000 deaths in a year, but move from that "C" to an "A". That is what I think the committee ought to strive towards.

In addition to pulling it together as a single concept, you need to move beyond understanding to some improvement strategies, linked closely to the idea of organizational and health systems' accountability and performance. Those are the things that will ultimately drive the system towards quality end-of-life care, in addition to the things we have done already in palliative care, at the clinical level and at education. Something new is needed. These are some innovations that will drive us in that direction.

Senator Beaudoin: You say something new is needed. We have definitions on refusal, withdrawing, withholding, sedation, palliative care -- perhaps I missed some; I apologize if I did. We do not have to improve that. It is clear-cut.

Dr. Singer: I agree. However, my point is that I practice at the bedside. If I am trying to teach a group of medical students or residents how to approach a dying patient who is in front of us, I can talk about advanced directives, I can talk about life-sustaining treatments, I can talk about pain, but those are little pieces of the puzzle. They still do not have a comprehensive way to think about it, like they have a comprehensive way to think about heart failure.

What we need to do is step back and ask what our goal is here. Our goal is to ensure that the patient in front of us receives quality end-of-life care. How do we do that? Every day we go to the bedside and ask: Are the pain and symptoms controlled? Have we had the discussions we need about life-sustaining treatments? Have we done what we can to support the patient and family? That may seem simplistic to you, but that is an example at the bedside level of an organized conceptual framework.

In my remarks, I have taken that same big-picture view to the level of health care institutions and have framed it as an issue of accountability and thought about how to start to measure it and improve it. It ties very well to my friend Dr. Chochinov's recommendations. In the annual report that he spoke about, what is it that you should have? You should have measures of how Canadian health care systems are performing on this important parameter called quality end-of-life care. Take that organized approach that we developed at the bedside and move it up to the organizational and health systems level in terms of recommendations that we can make in that regard. If I go to the bedside, I talk to the resident or the medical student about a little piece of the puzzle at a time. It will be hard for them to move forward, because they do not see the big picture. The big picture is quality end-of-life care. The third level you have to go to is to think about some improvement strategies for that target.

Dr. Chochinov: Many of the discussions talked about the hurdles and difficulties euthanasia and assisted suicide euthanasia create in this discussion and about that being an impediment to moving the agenda forward. There are two others that we have not discussed. The first is, perhaps, a lack of political will. Unfortunately, in end-of-life care, we do not have a vocal constituency. The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak. That is a problem.

The second issue is something that we touched on in some earlier testimony, namely, the issue of funding and funding for research. Research funding is necessary to generate knowledge, and knowledge defines the ceiling. The level of care can only rise as high as that ceiling. Let there be no confusion. There was some discussion wherein we were told there was not enough funding and then later on that, perhaps, there was enough funding. I will be the tie-breaker: There is insufficient funding for end-of-life care research.





I was involved in a project funded by Health Canada to create a national palliative care research agenda. I would be happy to submit the findings of that report. It used an external consultation report that looked at each of the major funding agencies in terms of the amounts of funds that are available. MRC, which has a global operating budget of \$200 million annually, could identify six grants in the last five years, only one of which was funded at the level of \$39,000. The National Cancer Institute of Canada did somewhat better. Of the moneys that they have given out in the last five years, \$500,000 was given to end-of-life care projects, which represents about .03 per cent of their operating budget. In this overview, it appears that Health Canada has funded about 25 projects, to the tune of about \$7 million. Looking over the list of those projects, most of them are educational initiatives and synthesis and dissemination projects.

Fundamental research needs to be done to generate the knowledge that will be disseminated. The gentleman from NHRDP indicated that \$1.2 million over the last five years has been spent on palliative care research. He provided me with a list of those projects. Approximately \$400,000 is related to synthesis projects, \$400,000 to support two career scientists, and the remainder for a smattering of small projects.

Let there be no confusion about the issue: We are woefully lacking funds. In preparing my comments for today, I spoke to a senior palliative care researcher this past week. That individual, who is considered one of Canada's pre-eminent researchers, indicated that there is uncertainty whether, in a year from now, there will be jobs. Frankly, it would be easier to be a research assistant working in someone else's lab than to deal with the frustrations of trying to find ongoing sustained support.

Senator Roche: What is the percentage of existing palliative care that is occupied by cancer patients?

Dr. Singer: I was going from the 222,000 people who die to say that about one quarter of them die from cancer. Most of the palliative care is focused in the cancer domain. Let us assume that half the people who die of cancer have access to palliative care.

Senator Roche: Is that an assumption?

Dr. Singer: Yes, these are assumptions.

Senator Roche: You are assuming that 50 per cent of people who die from cancer have access to palliative care?

Dr. Singer: That is a complete guess.

Senator Roche: Your friend is not agreeing with you.

Dr. Chochinov: With all due respect, I think the answer is probably considerably lower. The importance of your point is still salient.

Dr. Singer: If it is one quarter, then it is 6.75 per cent. You must think of the following from a population-based perspective: Annually, about 222,000 people die. You want access to palliative care for many of them, and funding for that should be increased for the ideal circumstances that you were hearing about in the previous circumstance. However, you will never get to the point of 100 per cent access for palliative care special expertise, and maybe you should not. Less than 100 per cent of people with heart failure are cared for by cardiologists. A lot of them are cared for by general internists such as myself. My point goes back to the integration issue.





Senator Roche: Are you making the point that more than the cancer patients who are dying require palliative care?

Dr. Singer: Yes.

Senator Roche: In other words, cancer patients get a head start into palliative care. Is that right?

Dr. Singer: Yes. Palliative care grew up, historically, from the Dame Cicely Saunders Hospice in the U.K. It grew up in the cancer model. The main point I am making is that it deals with one quarter of the deaths.

Senator Roche: You say that palliative care includes but goes far beyond cancer?

Dr. Singer: Yes, and in two ways. First, you want organized palliative care specialist services not only for the quarter of people with cancer but also for all deaths <#0107> that is, other than the 10 per cent of people who have sudden deaths.

Second, you do not want to think about dealing with this access issue only as an issue of increased specialist services; rather, you also want to build the skills of front-line doctors and nurses who are caring for those 222,000 people who die, their own core competencies in end of life. I am coming back to the issue that was raised earlier, namely, that every practising physician or nurse who deals with dying people, while not a palliative care expert specialist certified by their college, should have the same level of core skills in end-of-life care as they do in treating people with health care or any other problem.

The Chairman: Thank you very much. It has been very informative. We will have to shut the cameras off now. I need the permanent members of the committee to stay. We must approve our budget for this coming session. I should like everyone to leave except those people required for our next discussion.

Honourable senators, we have a budget to approve. As you can see, the amount is very small -- namely, \$7,890. Item 2 is video conferencing. That item would be to update the information, because our second mandate was to update information that was in the other report. At this point, I am not sure we necessarily want to use that process. We may want to use the researchers.

My first recommendation is that we get the information from the researchers about what has happened in the Netherlands, Australia and Oregon. If we then feel it is necessary, we can do a video conference with one, two or three of those countries. However, I want it in the budget so that we will have the money if in fact we agree to proceed that way.

Senator Corbin: That is a reasonable approach.

Senator Beaudoin: I do not object to that because there is some flexibility here. However, it is difficult to agree with Oregon because it is only one state. Why not England or another country?

The Chairman: Because the others have not moved into this area. In our original report, we looked at all other countries that had a policy with respect to euthanasia and assisted suicide. You will remember our video conference with representatives from the Netherlands.

Senator Beaudoin: Yes.

The Chairman: At that point, they were the only ones; there was no others. The only jurisdictions that have changed between 1995 and now are Northern Territory in Australia, the State of Oregon, and the



Netherlands, which has introduced legislation, although it is not yet passed.

Senator Beaudoin: What happened in Oregon?

The Chairman: They have had legislation in Oregon since 1995.

My recommendation is that we allow our researchers to get us the information. If we are content with the information they have given us and we it becomes unnecessary to proceed with video conferencing, then we will not have a video conference; we will simply use that information to update our report.

My concern is the concern that was expressed by the last two witnesses. I do not want us to get off focus at all. I want our focus to be quality death in Canada and not the issue of euthanasia and assisted suicide.

If someone will move that, I can present it to Internal Economy.

Senator Beaudoin: How many members are we?

The Chairman: There are three of a total of five here today.

Senator Beaudoin: I may move it. I have no objection.

Senator Corbin: I am thinking. Northern Territory of Australia, the Netherlands and Oregon allow euthanasia, so what is the point of discussing that issue with them?

The Chairman: We have not made a decision about whether we intend to, but one of our mandates is to update the information of the 1995 report.

Senator Corbin: Even the Netherlands did not contribute much in terms of what we are reviewing, the palliative care context. We were more interested in finding out about their euthanasia policy and approaches. Therefore, I do not believe a discussion with them would be relevant. In fact, I do not see why we would bother talking to Oregon at all.

The Chairman: We are not making that decision today.

Senator Beaudoin: I would not object at all to asking for \$5,000 for video conferences. I find that quite reasonable. I am inclined to agree that the choice may not be too good, as we will not hear very much from them.

Can we simply ask for \$5,000?

The Chairman: In other words, do not mention the countries?

Senator Beaudoin: Yes.

The Chairman: I do not see why not. That is not a problem. We could eliminate mention of the countries. Then we will have it in the budget and we can decide which countries we wish to have a video conference with.

We will eliminate reference to the countries and simply say "video conferencing". Before we do any video conferencing, we will have an in camera meeting about that.

Is that agreeable?





Senator Corbin: I would much rather get the research staff going on that area, which is our sector of interest at this time. If we talk to Oregon, we would have to talk to New York State, which rejected euthanasia, for all sorts of considerations.

Senator Corbin: I move adoption.

The Chairman: It has been moved and passed.

The subcommittee adjourned.









Français

# Proceedings of the Subcommittee to Update "Of Life and Death"

## Issue 5 - Minutes of Proceedings

OTTAWA, Tuesday, February 29, 2000

(7)

[English]

The Subcommittee to update "Of Life and Death" met this day in Room 257, East Block, at 8:30 a.m., the Honourable Sharon Carstairs, Chair, presiding.

*Members of the committee present:* The Honourable Senators Beaudoin, Carstairs, Corbin and Pépín (4).

*In attendance:* Mollie Dunsmuir and Nancy Miller-Chénier, Research Officers, Research Branch, Library of Parliament.

*WITNESSES:*

*From the Council on Aging of Ottawa-Carleton:*

Prof. David Bernhardt, President;

Marian Chapman, Chair, "Of Life and Death" Update Task Force.

*From the University of Toronto:*

Dr. Douglas Martin.

Pursuant to its Order of Reference adopted in the Standing Senate Committee on Social Affairs, Science and Technology on Monday, November 29, 1999, the subcommittee continued its examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death". (*For full text of Order of Reference please refer to Issue No. 1.*)

The Chair made an opening statement.

Marian Chapman and Prof. David Bernhardt each made a statement.

Douglas Martin made a statement



The witnesses answered questions.

At 9:48 a.m., the committee adjourned to the call of the Chair.

*ATTEST:*

Heather Lank

*Clerk of the Subcommittee*







Français

# Proceedings of the Subcommittee to Update "Of Life and Death"

## Issue 5 - Evidence

OTTAWA, Tuesday, February 29, 2000

The Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 8:30 a.m. to examine the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death."

Senator Sharon Carstairs (*Chairman*) in the Chair.

[*English*]

The Chairman: Honourable senators, today is our fifth day of hearings under our mandate to update the recommendations of the 1995 report on euthanasia and assisted suicide entitled "Of Life and Death". I would remind honourable senators, witnesses and those watching that this committee is not reopening the debate on assisted suicide and euthanasia. It is dealing strictly with the areas of the report where the original committee made unanimous recommendations. I ask you to bear that in mind as we proceed.

Before us today is Marion Chapman, Chair, "Of Life and Death" Update Task Force from the Council on Aging of Ottawa-Carleton. She is joined by Professor David Bernhardt, President of Canadian Council on Aging. We also have Dr. Douglas Martin from the University of Toronto. I welcome you all to our committee. I must also tell you that we have a special problem today, in that an emergency caucus has been called for ten o'clock, and we must finish shortly before then in order that Liberal members can get to that caucus.

Let us begin with Ms Chapman.

Ms Marian Chapman, Chair, "Of Life and Death" Update Task Force, Council on Aging of Ottawa-Carleton: Madam Chair and honourable senators, the Council on Aging is honoured to be invited once again to address your committee. We called together the group who met five years ago. A few were too frail, and the two francophone members were away, but we remain 12 strong with the addition of the present president and vice-president.

One true story set the stage for our discussion on advance directives, and I would ask Professor Bernhardt to share it with you.

Professor David Bernhardt, President, Council on Aging of Ottawa-Carleton: I am, as has been





mentioned, President of the Council on Aging of Ottawa-Carleton, and for the past 35 years I have been a member of the Psychology Department of Carleton University. I am here to support Ms Chapman, our past president, in her presentation, which, as President of the Council on Aging, I have approved and authorized.

For the past 18 years, my mother lived in a seniors' residence in Toronto with some 200 other seniors. Unlike most of the residents there, she had signed an advance directive that, among other things, included directions not to resuscitate. In August of 1999, shortly before her ninety-sixth birthday, as she returned from the dining room outside the nurses' station, where her advance directive was housed, she dropped dead. An ambulance was called and within minutes the paramedics arrived. For the next hour, they attempted unsuccessfully to revive her.

This story illustrates two of the significant concerns of our presentation: that most seniors have not set up advance directives and that, even when they are set up, they are not always followed. As Ms Chapman has said, this particular story was one that we turned to repeatedly as we went through our deliberations.

Ms Chapman: The Council on Aging of Ottawa-Carleton is a bilingual, non-profit, voluntary organization dedicated to enhancing the quality of life for all seniors in Ottawa-Carleton. The council works with and for seniors to voice issues and concerns to all levels of government and to the general public.

In 1995, the Special Senate Committee on Euthanasia and Assisted Suicide held hearings on issues related to death and dying. The Council on Aging of Ottawa-Carleton was pleased to participate in those hearings. At that time, our brief discussed such issues as palliative care, advance directives, individual rights, and the law and legal options. We made recommendations to the committee on those issues.

Today, it is our understanding that the focus of this hearing is on advance directives. It has been useful for us to examine our original position in relation to the recommendations in the report and in relation to the Ontario provincial legislation, the Health Care Consent Act of 1996.

In 1995, we presented principles to guide discussion, and I hope there is time to read them. I feel they are just as significant now as they were then, and they really apply to the advance directives. The council has the basic belief that every human being of adult years and sound mind has the right to determine what shall be done with his or her own person. From this, the Council developed the following 10 principles:

1. We believe in the inherent worth and dignity of every person;
2. We believe in justice, equity and compassion in human relations;
3. We support and promote the concepts of autonomy, independence and informed choice;
4. We acknowledge the diversity of the senior population in relation to culture, religious beliefs and language, and we respect the rights of individuals to make individual decisions based on these realities, which is particularly important as our population is changing;
5. We believe that seniors should be informed regarding all aspects of issues that impact on their well-being in order that they may make informed choices regarding the physical, mental and social aspects of their treatment and care;



6. We believe that individuals have the right to expect a death with the best pain control possible;
7. We believe that all seniors have the right to make decisions regarding a dignified dying process and death;
8. We recognize that there are differences in individuals' perceptions of what constitutes quality of life;
9. We believe that all individuals with a terminal illness should have access to palliative care services that include skilled, compassionate care and pain control; and
10. We believe that if persons are not able to make decisions for themselves, that their committee, a person to whom the care of a mentally incompetent person or his or her property was entrusted by a court, or attorney for personal care be given adequate information, counselling and support in making these decisions.

As people on the committee commented on our brief, I received many phone calls saying how important that support was, both during the process and after any decisions are made. We still believe that any discussion on advance directives must follow these principles.

With respect to the recommendations in your report "Of Life and Death", our 1995 brief to the Special Senate Committee spoke to the issue of advance directives and the importance of recognizing an individual's wishes regarding level of care and the importance of full information regarding advance directives for the individual, his or her family, the attending physician, and any institution involved.

We recommended that advance directives be enshrined in provincial legislation across Canada to facilitate the individual's wishes concerning either the level of care or the withholding or withdrawal of treatment as he or she reaches the terminal stages of life. We were pleased to see your report's recommendations, which I will cite again:

The committee recommends:

those provinces and territories that do not have advance directive legislation adopt such legislation.

the provinces and territories establish a protocol to recognize advance directives executed in other provinces and territories.

Where is the Council on Aging today? The council still adheres to its 1995 recommendation in respect of the assured availability of advance directives in every province and territory and, as a consequence, the recognition of advance directives from other provinces and territories. In Ontario in 1996 the Health Care Consent Act was adopted; it recognized and set conditions for the use of advance directives. The Council on Aging supports the principles contained in this legislation as an important step toward facilitating an individual's wishes about the conduct of the final stages of his or her life. In particular, the legislation covered the following principles, and we list only a few:

An individual has the right to choose treatment, including withholding or withdrawal of treatment and levels of care, to choose admission to a care facility and to choose personal assistant services;

The right to choose is based on informed consent and conditions to determine if appropriate consent was given. It must be related to treatment, be informed, be voluntary, and not be the result of fraud or misrepresentation;





Competency is defined as the ability to understand information and to appreciate the consequences of treatment. Recognition is given to competency in some areas and not in others;

Provision is made for situations of incompetency through the use of advance directives, either through instruction directives, or proxy directives, or through surrogate decision-makers;

A "best interests judgment" protocol is established for surrogate decision-makers in order to reflect the values and beliefs of the individual concerned, and to consider such factors as whether treatment is to improve, to maintain, or slow the deterioration of the individual, encompassing as well whether treatment could be used to relieve suffering even it means the shortening of life; and

The legislation provides for a process to recognize loss of competency, return of competency, and the right to change instructions.

As a result, there were certain issues that the Council on Aging addressed. The Council on Aging, however, is concerned about provisions in the legislation permitting health care professionals to take over treatment of an individual in emergency situations contrary to his or her explicit instructions. Here a mechanism should be developed to ensure that the individual's explicit wishes are respected in these circumstances.

Attached as an appendix to our brief is a sample of a series of possible advance directives provided to palliative care patients at the Sisters of Charity of Ottawa Health Service. They illustrate the range of choices for an individual in the terminal stages of life. I will not read those, but they are there for your information.

The Council on Aging remains concerned about the issue of portability of advance directives, that each province and territory recognize properly executed advance directives from other provinces and territories. Portability of advance directives between sites -- home, hospital, institutions -- is essential in order to maintain a consistent level of care. This is an important issue that continues to need attention, and we ask that your report emphasize this.

However, an equally important issue is the need for public education about choices regarding the final stages of life, choices that go beyond simply having a will and an arranged funeral. Through public education, the value of an advance directive can be reinforced. For the individual this means that his or her wishes will be respected. For family and caregivers the stress of making decisions at a time of uncertainty can be avoided. This information -- and we are thinking in terms of federal initiatives -- could be transmitted through inserts with Old Age Security pension cheques or Revenue Canada inserts, for example.

The final issue addressed by the Council on Aging concerns the availability of information contained in the advance directives to those who must act on it. The individual, or his or her substitute decision-maker, has the responsibility to inform health care professionals and care facilities of the existence of an advance directive. This can be of critical importance in case of emergencies. The Council on Aging recommends the development of a recognizable wallet-sized card or bracelet, carried or worn at all times, that would outline the individual's wishes or where that information can be found.

In our technological age one would think one could do these things. Good communication between the individual, the family, the substitute decision-maker, the physician, health care providers and the lawyer, who is drawing up these directives, is essential both in the development of an advance directive and in its implementation.





In summary, in updating its 1995 deliberations on advance directives:

The Council on Aging reaffirms its original recommendation;

The Council on Aging supports the recommendations concerning advance directives contained in the Senate committee report "Of Life and Death";

The Council on Aging supports the portability of advance directives, both between provinces and territories and between sites -- homes, hospitals, institutions;

The Council on Aging recommends clarification regarding the use of advance directives in emergency situations so that an individual's wishes may be respected;

The Council on Aging recommends the development of a public education campaign to encourage the use of advance directives; and

The Council on Aging recommends the development of a means of readily accessing the information in an advance directive.

Dr. Douglas K. Martin, Research Associate, Joint Centre for Bioethics, University of Toronto: Madam Chairman, honourable senators, it is a great privilege for me to address you today concerning advance care planning and its role in Canadian policy regarding end-of-life care. My statement will consist of two parts. First, I will review the meaning and purpose of advance care planning. Second, I will make recommendations for your consideration.

Quality in end-of-life care is increasingly recognized as a health care issue that deserves more attention. Four in ten people die in severe pain. Incurably ill patients with advance dementia receive non-palliative treatments. Improving the quality of care available to the 220,000 of our fellow Canadians who die each year is a moral imperative.

Advance care planning is an important part of initiatives to improve end-of-life care. Advance care planning may, and often does, include written advance directive forms. The concerns associated with advance directive forms are well documented. People like them, but, they do not use them. Interventions have increased the use of advance directive forms, but only to modest levels. When decisions need to be made, advance directive forms are difficult to interpret. The key question is "Why?" One answer may be that our traditional understanding of advance care planning was not rooted in the needs and experiences of patients.

Traditionally, advance care planning was assumed to help people prepare for treatment decisions in times of incapacity, to be based on the ethical principle of autonomy, to focus on the completion of written advance directive forms, and to take place within the context of the physician-patient relationship. In a series of research studies at the University of Toronto, we asked patients who were involved in studies of advance care planning what it meant to them. From the perspective of patients, advance care planning helps patients prepare for death. It is influenced by social relationships, is a process of communication, and takes place in the context of people and their loved ones.

From the perspective of patients, advance care planning helps people prepare for death and dying. People in our society are struggling to find ways to cope with death. Once a central ritual of social and religious life, death has been privatized, desacralized and hidden behind institutional walls.



Advance care planning can help people face death and prepare for dying, which from the patient's perspective means three things: achieving a sense of control, relieving burdens on loved ones, and strengthening relationships with loved ones.

Advance care planning helps people achieve a sense of control by helping them focus on the larger issues related to dying. Autonomy is central to advance care planning but not primarily in the sense of micromanaging each treatment decision. Emphasizing informed consent for each treatment decision is probably a way to avoid confronting the larger issue of death and dying. Although informed content for treatments is legally required and therefore necessary, it is not sufficient. Patients want a voice in their end-of-life care rather than control over each treatment decision.

Advance care planning helps people relieve burdens on loved ones. Patients fear that their dying may place upon their loved ones three burdens: witnessing their death, providing physical care, and substitute decision-making for life-sustaining treatments.

Advance care planning helps people relieve burdens on their loved ones by helping determine settings for care and limits for life-sustaining treatments. It helps prepare loved ones who may serve as substitute decision-makers in a crisis.

Advance care planning helps people strengthen relationships with loved ones. Facing death in the context of loved ones, may be an important redeeming accomplishment. People live in a web of social ties and often fear dying in isolation. Dying offers important opportunities for growth, intimacy, reconciliation and closure in relationships.

To summarize, advance care planning is a process of communication that helps people prepare for death in the context of their loved ones. However, often when we think of advance care planning we think of advance directive forms. So what is the role of the advance directive form?

From the patient's perspective an advance directive form is not the central or defining feature of advance care planning. Advance care planning is a process of communication, and advance directive forms are best viewed as an assisting device embedded in the advance care planning process.

Many people consider themselves satisfied with their advance care planning without the completion of an advance directive form. They use advance care planning to prepare for dying and are often satisfied that discussions achieve that goal.

Advance directive forms can facilitate advance care planning by serving as educational tools or worksheets that can guide discussions about death and end-of-life care. Thus, an advance directive form is not simply a legal document that records a person's proxy choice and treatment preferences. In addition, when substitute decision-makers must make difficult decisions concerning life-sustaining treatments, advance directive forms can provide guidance and support, which may mitigate any guilt decision-makers might experience over their decisions.

However, advance care planning is only one piece in the broader picture of end-of-life care. Your 1995 report "Of Life and Death" was an important benchmark in the development of quality end-of-life care in Canada because it dealt with advance care planning and also three other topics of clear importance to Canadians who are dying -- namely, palliative care, pain control and sedation, and withholding and withdrawing life-sustaining treatments.

In the context of research conducted at the University of Toronto, dying patients repeatedly told us that





they define quality end-of-life care as: adequate pain and symptom control; appropriate use of life-sustaining treatments; and support of patients and families. From the perspective of patients, "Of Life and Death" was right on target.

"Of Life and Death" was also extremely valuable because it reinforced the critical distinction between these important issues in quality end-of-life care, on the one hand, and euthanasia and assisted suicide, which are not important to, and may detract from, quality end-of-life care on the other hand.

Let me now turn to what the Senate of Canada can do to help improve end-of-life care for the 220,000 Canadians who die each year.

First, when you update "Of Life and Death," include a chapter that draws together issues in pain and symptom control, appropriate use of life-sustaining treatments and support for patients and families into a coherent, conceptual framework of quality end-of-life care in Canada. This single, unified conceptual framework can then ground the development of indicators of quality end-of-life care and, subsequently, strategies to achieve them.

Second, when you update "Of Life and Death," ensure that the importance and role of advance directive forms are put in their proper context. Although recognized in legislation, advance directive forms are not simply legal documents that record a patient's preferences. They are primarily tools that can facilitate discussions between people and their loved ones, and they may provide guidance and support for substitute decision-makers who must make difficult decisions regarding life-sustaining treatments.

In your update, emphasize that patients consider advance directive forms neither necessary nor sufficient. Therefore, advance directive forms should not be mandatory, and advance care planning should not be evaluated by rates of advance directive form completion. From the patient's perspective, advance care planning is a process of communication between people and their loved ones that helps them face death and prepare for dying.

In closing, let me say thank you again for the privilege of speaking to you on this important topic. I would be honoured to work with you to improve the quality of end-of-life care available for you, for me and for our fellow Canadians.

The Chairman: Thank you very much, Dr. Martin. We will begin with the questions.

Senator Beaudoin: Thank you for your very good presentations.

We agree, of course, that we should have advance directives, and we know that it is not the case in every province of this country. However, I was a bit surprised to hear Professor Bernhardt say that, although his mother, if I understood correctly, had an advance directive will, they tried to resuscitate her, and did so for one hour.

Mr. Bernhardt: One hour, yes.

Senator Beaudoin: Surely we should avoid that kind of situation, but what is the best means to achieve that goal, in your opinion? She had an advance directive and it was not very useful. Should it be registered? In my own province, Quebec, if you have a testament or a will it is registered, and we may always find that; but in the other provinces is it the same thing, when they have wills? Should the advance directive be registered? How do you envisage getting rid of that problem?





Mr. Bernhardt: This is something that certainly our committee struggled with. As Ms Chapman has mentioned, we struggled with finding some way of identifying that the individual has this advance directive.

In the case of my mother, she was living in a seniors' residence, and she died just outside the nurse's station where the advance directive was housed. But there are two things involved here. First, the individuals who were there in the evening were not aware of the directive's being there, and, second, there is the problem that once an ambulance is called, there is a requirement to do what can be done to save the life of the individual.

Certainly, this tends to be somewhat of a contradiction as far as these two pieces of legislation are concerned.

*[Translation]*

Senator Beaudoin: The Senate is an important legislative chamber and our role is to improve legislation. Dr. Martin, you are asking us to pass legislation concerning advance directives. Death is an inevitable fact of life and it is better that we be proactive on this front.

Refusing treatment and the withdrawal of instruments in the final stages of a person's life are largely matters that should be dealt with in provincial and, obviously, in federal legislation. What kind of federal legislation would you like to see in place?

*[English]*

Mr. Martin: That is a good question. It highlights the key issue that advance directives will not solve the problem and avoid situations as were described here.

Senator Beaudoin: They are helpful, but they do not solve the problem entirely.

Mr. Martin: In the kinds of situations we are discussing here, the issue was that the focus was on the form and the form was not useful. If the form is in a drawer somewhere or, worse, locked in a security deposit box somewhere, it is of no help to anyone. The key message here is that advance directives do not speak to health care professionals; advance directives speak to substitute decision-makers. In the case described by Professor Bernhardt, the substitute decision-maker becomes, in a de facto way, the nurse or whoever called the ambulance. In the process of communication that prepares substitute decision-makers, whoever takes on that role must be prepared and must know what the person's wishes are in the event of the kind of emergency described. If they are not part of that communication process, a form will not help them.

*[Translation]*

Senator Beaudoin: A legal document is a document intended for the public's eyes. When a person's draws up a will, that person's wishes must be respected. If you state in your will: "The following directives are to be followed in the event I become seriously ill or mentally incapacitated", then your final wishes must be respected. I think the Mandate in Case of Inability, or power of attorney in case of incapacity, is directed to everyone. The proof is that it is supported by provincial legislation.

*[English]*

The same thing happens with respect to withholding an instrument or refusing treatment. It is addressed



to everyone, and that is why, in my opinion, we should enshrine it in a statute so that everyone will be bound by the law. You can say, "Well, it is not addressed to the professionals," but the law is binding for everyone.

Mr. Martin: I understand your point, and I think you are trying to achieve a noble end. However, there are two problems with making an advance directive mandatory. One is that it is not always there. In this case, it was in a drawer somewhere. It may be at home. It may be in your purse.

Senator Beaudoin: That is not useful.

Mr. Martin: It is not useful if it is not present, and a piece of paper is not necessarily present. Second, it is not always clear. It is too often vague, too often unspecific, too often difficult to interpret. Some people may write on their advance directives, "No heroic measures." What does that mean? People in the midst of a crisis must interpret that, and it becomes impossible. Because of the problem of visibility and also because of the problem of clarity, advance directives are a useful tool, but they will not solve this problem. The only way this problem can be solved is to have decision-makers on the spot who are prepared in an emergency situation, as described. If it cannot be a family member or a loved one, and they cannot be there 24 hours a day, whoever is there must be prepared and must be included in the circle of communication.

Ms Chapman: You were pointing out the issue we were addressing: Having something on the person at all times, whether it is a bracelet with information on it, a card with information on it, or a place where that information can be retrieved.

In the 1996 legislation, the Consent to Treatment Act in Ontario, the advance directive can be in many forms. It can be a form, as Dr. Martin mentioned, but it can also be oral. It can be changed at any time, so that the last information you gave your daughter supersedes what you gave your son six months previously. Therefore, there is this difficulty with the advance directive not being in a form, such as a will, that can be made a legal entity. If you have a substitute decision-maker, though, I understand that you do have a legal document that defines that person.

*[Translation]*

Senator Pépin: I understand Senator Beaudoin's legal approach to this matter, but when feelings are involved, I prefer to stay away from legal considerations, because it is quite difficult to bring legalities into this. However, on a preventive level, there are certain things that can be done.

In seniors' residences, different colours are used on charts to indicate whether a patient has diabetes, a heart problem and so forth. Nursing staff should be trained to ask seniors what their preferences are as soon as they are admitted to care.

Steps should also be taken to sensitize staff to the wishes of seniors. I think the idea of a bracelet is a good one because on seeing the bracelet, emergency care workers would immediately know what the patient's wishes were, even if that patient had never openly expressed them.

The education and training process could involve a push to encourage people to wear a bracelet like this or to carry a card. Whether in a hospital setting or seniors residence, the nursing staff should always be aware of a person's last wishes or of the location of the advance directives. Are you recommending something similar to this?





[English]

Ms Chapman: It is important to have those instructions known ahead of time. In talking to a member of the Ontario Ministry of Health in long term care yesterday, they are not stipulating that one must have an advance directive before going into an institution. Therefore, it becomes facultatif -- you can have it or not. It is very difficult to legislate that one must have an advance directive. The answer may be that there should be a public education program advising that it would be in your interest to have it.

Senator Pépin: In your presentation, you state:

Competency is defined as the ability to understand information and to appreciate the consequences of treatment. Recognition is given to competency in some areas and not in others;

Which areas are not included?

Ms Chapman: That is straight out of the Health Care Consent Act.

Senator Pépin: Could you give me an example of an area which is not included?

Ms Chapman: If someone is very seriously ill, he or she could be competent in the sense of being a capable individual, but not really capable, at that time, of being able to make decisions. Thus, someone would need to make decisions on behalf of that person. That would be my understanding of the situation.

Senator Corbin: In your opinion, is there a Canadian policy regarding care at the end of life? I would refer to your first statement.

Mr. Martin: The policy regarding end-of-life care in this country is evolving in the same way that it is evolving in many other countries. That is, it is evolving, one narrow piece at a time.

Senator Corbin: Jurisdiction by jurisdiction?

Mr. Martin: Issue by issue. Palliative care, decisions regarding life-sustaining treatments, pain and symptom control, euthanasia and assisted suicide, advance directives, are all pieces. They are all evolving at their own rates and own time, according to front pages of the newspapers and particular issues upon which the legislatures focus. It is the same in the U.S. and in Europe.

The problem is that individual pieces of end-of-life care are evolving in different directions at different rates. There is no coherent framework to draw them together.

Senator Corbin: It is a piecemeal approach.

Mr. Martin: Yes. You probably recognize that many of my remarks are similar to those made by Dr. Singer yesterday. In this country, we need a national strategy for improving end-of-life care -- a holistic approach, a unified framework that incorporates all these pieces into an identifiable goal of improving end-of-life care for the 220,000 people who die each year in this country. That does not exist currently.

Senator Corbin: I will move on to another part of your statement. You comment on page 2 of your presentation that AD forms are difficult to interpret. Where does the problem of interpretation lie? Is it with the professionals in medicine? Is it a language issue? What specifically is the major challenge there?





Mr. Martin: That is an excellent question, and one that I think could evoke multiple answers. Let me give you my opinion on it.

An institution, such as a hospital or a health care facility, embodies certain institutional values. An individual embodies values. The advance directive form is supposed to translate an individual's values into the language of the institutional values. It cannot.

I can bring before you a 50-page advance directive, with details that are minutiae, to say the least. You would not be able to interpret it. It is that much more difficult when the information is on a bracelet, which has very little room for explaining your values and why you want what you want.

The simple fact is that a tool such as a piece of paper or some other medium may not be sufficient. I have seen a person who had a tattoo on their chest with the picture of those resuscitation paddles and a big line through it. That is an advance directive. What does it mean? It is the same whether you have a bracelet, a form, or whether you can say words like "no heroic treatment" or "no life-sustaining treatment".

What does that mean, and in what circumstances does it apply? The key issue is communication. It involves a discussion of values with those involved. There must be discussion of what is important and why it is important. That cannot be communicated through a simple tool.

Senator Corbin: Thank you very much for clarifying that.

I have one final point to raise for this round. It concerns all three of you, if I may say. The council takes objection, or worries...

[*Translation*]

The Council on Aging is concerned about provisions in the legislation which allow health care professionals to take over treatment of an individual in "emergency" situations.

[*English*]

Dr. Martin also referred to substitute decision makers in a crisis. In such situations, health professionals can, and indeed do, go in opposite directions to the express wishes of the patient. The council suggests that we should design a mechanism to ensure that the explicit will of the person would be respected in such urgent or crisis situations.

I wonder why this was introduced in the Ontario law in the first place. Would it not be, first and foremost, to protect health care professionals -- to reduce their liability, or are there other considerations?

Ms Chapman: Certain sections in the Health Care Consent Act provide that the health care professionals are not deemed liable for taking over. However, you are right in saying that it can be seen as a liability issue.

For our point of view, there is one very glaring problem area. It involves ambulance workers. If a person is being transferred from one institution to another, having had perhaps treatment at one place and is going back to another, or being transferred to a palliative care hospice from an acute care place, and if the person has a cardiac arrest during that time, the person must be resuscitated even if there is a Do Not Resuscitate order. It is that kind of issue that we find very difficult.



In emergency situations where it seems black and white to the individual, the person who has power of attorney for the person is not able to speak. However, we also realize the complexities of what happens in the emergency situation. The Ontario legislation does allow the health care professional to assess and determine whether in fact some treatment is necessary. We need to keep the person with the power of attorney apprised all along the way so that he or she knows when it is time to step in and say "yes" or "no" to certain treatment.

In our discussions with our group, we found that the emergency issues are complex. They are not simple issues. We, as individuals dealing with the health care professionals, need to be educated and we need support and help in making those decisions.

Mr. Martin: I might just take few seconds to try to put this very important issue into context. In all of Canada, in every province, before an individual treatment can be applied, informed consent must be given by the individual. That applies across the board. If an individual is incapable of giving consent, then a substitute decision maker must give consent before treatment can be started. We are talking here about an exception to that general, broad, countrywide law that applies to every single treatment. That exception is when there is an emergency situation and consent cannot be achieved. A health care professional is then mandated to do what is in the best interests of that patient, according to their standards and practice.

This particular problem, although important, arises less than 1 per cent of the time. Let us keep that in focus here. The Ambulance Act does not concord with the rest of the health care consent acts, and that is an important problem. The issue is consent. Consent is mandatory except in certain circumstances of emergency when consent cannot be achieved.

The Chairman: Dr. Martin, while I agree with 99 per cent of what you have said, I disagree with 1 per cent. Of the nine of us sitting around this table, two of us have been in situations where our mothers, who had "Do Not Resuscitate" orders on their medical charts, were given treatment despite their clear statement to the contrary. In my own view, it is an abusive use of power on the part of the medical professionals, whether they are ambulance workers or physicians. In my case, it was done by a physician despite the "DNR" on her chart. Unfortunately, ambulance attendants are faced with a more difficult issue because they have to conform to their rules which compel them to do this.

My disagreement with you comes from your statement that advance directive forms are neither necessary nor sufficient. I would agree with you totally that they are not sufficient because of your whole thesis, which is extremely supportive, that it cannot take place in isolation and that you need a whole care plan involving all of the people. Surely you must believe, as I do, that the advance directive is frequently the means by which this care plan is developed.

Mr. Martin: I do not think we are in so much discord. The example highlighted by Professor Bernhardt's evidence is that the advance directive did not work. It was there. She filled it out. It said, "Do not resuscitate". It was in a drawer somewhere. The nurse called the ambulance, and they resuscitated. It did not work. It is not always present, and when it is present it is not always clear. You need human beings to interpret the general guidance provided by directives. In that particular case, if trusted loved ones are not present, then whoever is present must be part of that, as you term it, care plan. Apparently, this nurse was not.

The Chairman: Surely that is a breakdown in the communication system.

Mr. Martin: Absolutely.





The Chairman: The care home, the seniors' home, the hospital, whatever, must have an adequate communication policy. That means that when nurses go on the seven o'clock shift, they sit down and assess the plans for the care of each individual patient. Surely that should be part of the information package. Should it not also apply to people who live in a senior citizens' home or, indeed, to people who live in their own homes?

Without the advance directive, which you state is not necessary, I would suggest to you that the discussions that are required will not happen.

Mr. Martin: I have talked to many patients in the conduct of research who do have those discussions without the completion of a form. Forms can be very useful. They can stimulate discussion. They can provide structure and guidance to discussion. In fact, the exercise of completing a form is a useful intellectual exercise in thinking through the issues and discussing them. They are very useful. However, when substitute decision makers are prepared, the forms are not necessary. They can be prepared through communication. Moreover, when the forms are completed, they are not always helpful. They are insufficient.

Mr. Bernhardt: Of a group of seniors, 30 per cent or so do not have loved ones consistently involved in the picture. In those particular situations, some form of advance directive certainly sets the stage for some consistency. In the situation where the family is not there and we have a revolving group of individuals associated with that senior, there is certainly a need for something to provide consistency that would not be there otherwise.

The Chairman: We heard one anecdotal report today, but I certainly know of others in which there is some confusion between the concept of power of attorney and advance directive. Would you like to comment on that? My 87-year-old father-in-law suffered from metastatic cancer. We did not have his power of attorney. We had his advance directive or living will. We knew what it was he wanted with respect to that. Frankly, there was no need for us to have the power of attorney. My experience was that people thought the two things were the same.

Mr. Bernhardt: In Ontario, certainly since this new legislation which has been in force for almost five years now, the situation has not become clear to most individuals. I find that very few individuals understand this division as far as the power of attorney is concerned and what is involved in that.

Ms Chapman: Under the legislation, if a person has not been named as a substitute decision maker, there is a list of people by a hierarchy who can speak for the person who is incapable of speaking for himself. I can give power of attorney to my daughter, but if I want it to have the force of a legal document, I must consult a lawyer and do it in a proper legal fashion.

Mr. Martin: This speaks precisely to Senator Corbin's question: Do we have a strategy for end-of-life care in Canada? We have a piecemeal approach. These things are called different things in different statutes. What can be more confusing? We have advance directives, living wills, powers of attorney for personal care, powers of attorney for health care, and so on. Advance directives have two parts -- the "who" part and the "what" part -- and the best way I know to confused the public is to call them by different names in different legislation. This highlights the problem raised by Senator Corbin -- that we do not have a unified approach to issues in end-of-life care in this country.

[*Translation*]

Senator P  pin: Under what circumstances might a decision be made to resuscitate a person despite the





existence of an advance DNR order?

[*English*]

Mr. Martin: People's wishes regarding what they want and what they do not want vary according to the state of their health, that is, it depends on what is wrong with them and how they feel. When they have problems that are reversible, they are more likely to want intervention. If they have problems that are not reversible, they are much less likely to want intervention. Therefore, a Do Not Resuscitate order must be linked to the state of health of the individual. That creates a second level of complexity. That, then, must be linked to the overall wishes of the individual regarding the quality of his or her life in general. That creates a third level of complexity.

I could go on, but I think you can see how quickly it becomes difficult to interpret what people mean when they say, for example, "If I am dying, let me die." If you stop breathing, are you dying? If you stop breathing and drugs can be administered or machinery can be used to help you breath again, are you dying? The situation is very confusing.

Senator Corbin: I will make a biographical revelation. I do not have an advance directive, and neither does my wife or my children, but we discuss this issue very comfortably quite often. In fact, it happened again last evening. That is fine as far as it goes. By that I mean I travel in my political work as a senator and my family may be far away. I may fall into the hands of unknown professionals in a strange hospital, and they do not know what my end-of-life or cultural or religious preferences are and, if I am comatose, they ethically must do what is best for me, according to accepted professional standards.

I am prepared to accept that. On the other hand, if I happen to go to hospital with my family present, I know they will do the right thing. In the end, it really does not matter. In an hour I will be dead or in two days I will be dead. They are left with many problems.

What we are discussing amongst ourselves is really a matter of easing the passage, making everyone comfortable, and by all means avoiding developing a sense of guilt. To me, there is a grave danger that the survivors may awake the next morning with a sense of guilt that they could have done more, or that the professionals could have done more. I do not wish to have too much legalese attached to end-of-life issues. This would create great opportunities to enrich already rich lawyers, and no matter what the law says in terms of liability in Ontario, for example, an enterprising lawyer can take anything to court and wreak havoc with the legal system. In the best of worlds, I like your soft approach, Dr. Martin. I categorize it as "soft" because it makes sense.

I do not know if I interpreted Senator Beaudoin's comments correctly, but Senator Beaudoin is a jurist. To his way of thinking, everything must be clear-cut in the law, and you must take into account all possible situations. To me, that is not what life is about. Life is a continuum, and I accept what life and death offer me.

Perhaps I went too far in telling you how I feel but, for God sake, spare us the legalese.

Senator Beaudoin: I must defend myself.

I think the "law of health", if I may refer to it as that, is just beginning. People are afraid of talking about death, sickness, et cetera. I am the first to admit that. I do not say that everything should be legalized. That is going much too far. I have prepared a will because, in my opinion, it is necessary.



However, I think it will become increasingly important to have legislation, in a general sense. Special arrangements can be made way of a will, and although you may write a directive, the question of interpretation is a major consideration. Even the most brilliant people sometimes do not express themselves clearly. This is part of life. We may try to remedy that, but it will always be there.

Therefore, I think we should have general legislation, but we should still allow everyone the option of preparing his or her own directive. I believe in that. I also believe that being able to designate the power of attorney is very useful. I do not have that, but I probably should.

The preparation of directives should be available but, in their absence and having regard to human nature, I believe it is the duty of Parliament to legislate generally, in the event that people do nothing. If people do not do anything, we will be stuck with the problem. It is a compromise.

There should be general legislation for practitioners, that is, doctors and nurses, but we must leave some decisions to the individual. The Charter of Rights and Freedoms is a very important statute. We may have wars, but we have charters to protect rights and freedoms.

We know we need some general principles to guide us and, within those principles, every individual would be free to do what he or she wants.

Civilization started with the enactment of laws, and we will always have laws. The law of health is just starting. I do not say that we must put everything in writing because that would be foolish, but we should put in writing the general principles which shall apply to everyone.

The Chairman: There is very little disagreement between the two senators. Senator Beaudoin is saying that everyone should have the right to make an advance directive if they want, and Senator Corbin is saying no one should be compelled. We are unified on that.

Ms Chapman: I would like to emphasize that the people sitting around the table at the Council on Ageing -- people from all different walks of life -- were very firm in their support for the need for an advance directive. They wanted to be part of the decision making that took place once they came to that interface and beyond with the medical profession.

You do your planning and thinking with family. That is important and, in fact, wonderful. However, that must carry over when dealing with the health care professionals.

It is absolutely essential that the thinking is done ahead, but then it must carry over into the other realm so that all those end-of-life issues can be carried out as determined by the person who must go through the whole process.

Mr. Martin: If the focus of general legislation setting out general principles is on advance care planning as a process of communication, then all these other things will follow quite naturally and in a common-sense manner. If you focus on the form, you will miss out on the social aspects of communication.

Senator Beaudoin: We are sensitive to communication.

The Chairman: I wish to put a question to Professor Bernhardt. Senator Corbin raised a very interesting point of view, and one in which I think he is absolutely correct. We die and it is the bereaved ones who are left with some sense of guilt that not everything was done that should have been done.





I, personally, have an enormous sense of guilt about the circumstances surrounding my mother's illness. She had had a cardiac arrest before, and knew she was likely to have others, so her Do Not Resuscitate order was very clear. If she had a cardiac arrest, she did not want to be resuscitated. She did not want to have the paddles applied. My guilt arises from the fact that they were applied. I have always felt that I let her down because, as her substitute decision maker, they did something without her permission, and with which I did not agree.

Professor Bernhardt, you have been in exactly the same situation. What was your reaction when you learned that they had tried to resuscitate your mother for an hour?

Mr. Bernhardt: I was not quite in the same situation you were in, and I did not feel the same sort of guilt. I was in Ottawa and she was in Toronto, thus I was not there. The resuscitation did not work, so there was not the same sort of situation that you faced. My bad feelings came when I went to Toronto to make the funeral arrangements and talked with mother's friends in the residence where she was living who had spent an hour there watching this. For them, this was a horrendous experience.

There was no reason for me to feel guilt, and I did not in that situation. The guilt was more in the fact that I was in Ottawa and she was in Toronto through this last 10 years of her life. It is very difficult to be a caregiver from a distance. That is where my guilt came in.

The Chairman: Thank you very much. It has been extremely useful to have had this discussion with you today. I can assure you that the views of all of you will form a significant part of our recommendations.

Senators, our next meeting is Tuesday, March 14, 2000. We have no meetings scheduled for next week because the Senate will not be sitting.

The committee adjourned.



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## ERRATUM

Issue No. 6

Second Session  
Thirty-sixth Parliament, 1999-2000

### SENATE OF CANADA

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*Standing Senate Committee on Social Affairs,  
Science and Technology*

*Proceedings of the Subcommittee to*

## Update “Of Life and Death”

*Chair:*  
The Honourable SHARON CARSTAIRS

Monday, March 20, 2000

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Issue No. 6

### Sixth meeting on:

Examination of the developments since the tabling in  
June 1995 of the final report of the Special Senate  
Committee on Euthanasia and Assisted Suicide,  
entitled, “Of Life and Death”

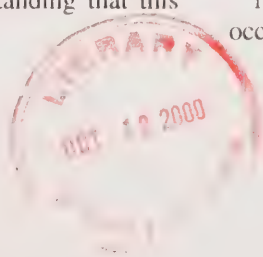
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## ERRATUM

Issue Six was incorrectly identified as the Seventh  
meeting and was published with the wrong date.

We regret any confusion or misunderstanding that this  
error may have caused.

WITNESSES:  
(See back cover)



## ERRATUM

Fascicule n° 6

Deuxième session de la  
trente-sixième législature, 1999-2000

### SÉNAT DU CANADA

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*Comité sénatorial permanent des affaires sociales,  
des sciences et de la technologie*

*Délibérations du sous-comité de*

## Mise à jour de «De la vie et de la mort»

*Présidente:*  
L'honorable SHARON CARSTAIRS

Le lundi 20 mars 2000

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Fascicule n° 6

### Sixième réunion concernant:

L'étude des faits nouveaux survenus depuis le dépôt,  
en juin 1995, du rapport final du comité sénatorial  
spécial sur l'euthanasie et l'aide au suicide, intitulé:  
«De la vie et de la mort»

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## ERRATUM

Le fascicule numéro 6 était en fait la sixième réunion et  
non pas la septième; et la date était en erreur.

Nous regrettons toute confusion ou tout malentendu  
occasionné par cette erreur.

TÉMOINS:  
(Voir à l'endos)







Second Session  
Thirty-sixth Parliament, 1999-2000

SENATE OF CANADA

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*Standing Senate Committee on Social Affairs,  
Science and Technology*

*Proceedings of the Subcommittee to*

## Update “Of Life and Death”

*Chair:*  
The Honourable SHARON CARSTAIRS

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Tuesday, March 20, 2000

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Issue No. 6

### **Seventh meeting on:**

Examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled, “Of Life and Death”

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WITNESSES:  
(See back cover)

Deuxième session de la  
trente-sixième législature, 1999-2000

SÉNAT DU CANADA

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*Comité sénatorial permanent des affaires sociales,  
des sciences et de la technologie*

*Délibérations du sous-comité de*

## Mise à jour de «De la vie et de la mort»

*Présidente:*  
L'honorable SHARON CARSTAIRS

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Le mardi 20 mars 2000

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Fascicule n° 6

### **Septième réunion concernant:**

L'étude des faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide, intitulé: «De la vie et de la mort»

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TÉMOINS:  
(Voir à l'endos)

THE SUBCOMMITTEE TO UPDATE  
"OF LIFE AND DEATH"

The Honourable Sharon Carstairs, *Chair*

The Honourable Gérald-A. Beaudoin, *Deputy Chair*

and

The Honourable Senators:

\* Boudreau, P.C.  
(or Hays)  
Corbin  
Keon

\* Lynch-Staunton  
(or Kinsella)  
Pépin

\* *Ex Officio Members*

(Quorum 3)

*Changes in membership of the committee*

Pursuant to rule 85(4), membership of the committee was amended as follows:

The name of the Honourable Senator Corbin substituted for that of the Honourable Senator Kirby (*March 20, 2000*).

The name of the Honourable Senator Kirby substituted for that of the Honourable Senator Corbin (*February 29, 2000*).

LE SOUS-COMITÉ DE MISE À JOUR DE  
«DE LA VIE ET DE LA MORT»

*Présidente:* L'honorable Sharon Carstairs

*Vice-président:* L'honorable Gérald-A. Beaudoin

et

Les honorables sénateurs:

\* Boudreau, c.p.  
(ou Hays)  
Corbin  
Keon

\* Lynch-Staunton  
(ou Kinsella)  
Pépin

\* *Membres d'office*

(Quorum 3)

*Modifications de la composition du comité:*

Conformément à l'article 85(4) du Règlement, la liste des membres du comité est modifiée, ainsi qu'il suit:

Le nom de l'honorable sénateur Corbin substitué à celui de l'honorable sénateur Kirby (*le 20 mars 2000*).

Le nom de l'honorable sénateur Kirby substitué à celui de l'honorable sénateur Corbin (*le 29 février 2000*).

**MINUTES OF PROCEEDINGS**

Monday, March 20, 2000

(8)

[English]

The Subcommittee to update "Of Life and Death" met this day in room 257, East Block, at 2:00 p.m., the Honourable Sharon Carstairs, presiding.

*Members of the committee present:* The Honourable Senators Beaudoin, Carstairs and Corbin (3).

*Other senator present:* The Honourable Senator Douglas Roche (1).

*In attendance:* Mollie Dunsmuir and Nancy Miller-Chénier, Research Officers, Research Branch, Library of Parliament.

*Also in attendance:* the official reporters of the Senate.

Pursuant to its Order of Reference adopted in the Standing Senate Committee on Social Affairs, Science and Technology on Monday, November 29, 1999, the subcommittee continued its examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death". (For full text of Order of Reference please refer to Issue No. 1)

**WITNESSES:**

*From the Department of Health Canada:*

Carole Bouchard, Manager, Office of Controlled Substances:

Dr. Brian Gillespie, Senior Medical Advisor, Bureau of Pharmaceutical Assessment.

*From the Council of Canadians with Disabilities:*

Mr. Hugh Scher, Chair, Human Rights Committee.

*From the Campaign Life Coalition:*

Mr. Peter Ryan, Director (New Brunswick).

*From the Euthanasia Prevention Coalition of Ontario:*

Mr. Alex Schadenberg, Executive Director.

*From the Alliance for Life Ontario:*

Ms. Jacki Jeffs, Executive Director.

*From Care in Dying:*

Mr. Mark Cameron, coordinator:

Dr. Joseph Ayoub, oncologist, Institut du cancer de Montréal.

*From Alberta Life Foundation:*

Mr. James Mahony.

The Chair made an opening statement.

Carole Bouchard made a statement and, together with Dr. Brian Gillespie, answered questions.

Hugh Scher made a statement and answered questions.

At 3:41 p.m., the committee suspended.

At 3:52 p.m., the committee resumed.

**PROCÈS-VERBAL**

OTTAWA, le lundi 20 mars 2000

(8)

[Traduction]

Le sous-comité de mise à jour de «De la vie et de la mort» se réunit aujourd'hui à 14 heures, dans la pièce 257 de l'édifice de l'Est, sous la présidence de l'honorable sénateur Sharon Carstairs (*présidente*).

*Membres du comité présents:* Les honorables sénateurs Beaudoin, Carstairs et Corbin (3).

*Autre sénateur présent* L'honorable sénateur Douglas Roche (1).

*Également présentes:* Molly Dunsmuir et Nancy Miller-Chénier, attachées de recherche, Direction de la recherche parlementaire, Bibliothèque du Parlement.

*Aussi présents:* Les sténographes officiels du Sénat.

Conformément à l'ordre de renvoi adopté par le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, le lundi 29 novembre 1999, le sous-comité poursuit son étude des faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du Comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé «De la vie et de la mort». (Pour le texte intégral de l'ordre de renvoi, voir le fascicule n<sup>o</sup> 1).

**TÉMOINS:**

*De Santé Canada:*

Carole Bouchard, gestionnaire, Bureau des substances contrôlées;

Dr Brian Gillespie, conseiller médical spécial, Bureau de l'évaluation des produits pharmaceutiques.

*Du Conseil des Canadiens avec déficiences:*

M. Hugh Scher, président, Comité des droits de la personne.

*De la Coalition Campagne vie:*

M. Peter Ryan, président, (Nouveau-Brunswick).

*De la Euthanasia Prevention Coalition of Ontario:*

M. Alex Schadenberg, directeur exécutif.

*De l'Alliance pour la vie (Ontario):*

Mme Jacki Jeffs, directrice exécutive.

*De Care-in-Dying Coalition:*

M. Mark Cameron, coordonnateur;

Dr. Joseph Ayoub, oncologue, Institut du cancer de Montréal.

*De l'Alberta Life Foundation:*

M. James Mahony.

La présidente fait une déclaration.

Carole Bouchard fait une déclaration et, avec l'aide de M. Brian Gillespie, répond aux questions.

Hugh Scher fait une déclaration et répond aux questions.

À 15 h 41, le comité suspend ses travaux.

À 15 h 52, le comité reprend ses travaux.

The Chair made a statement.

Peter Ryan made a statement.

Alex Schadenberg made a statement.

Jacki Jeffs made a statement.

Mark Cameron and Dr. Joseph Ayoub each made a statement.

James Mahony made a statement.

Senator Corbin made a statement regarding his position on the 1995 recommendation about creating a third category of murder.

The witnesses answered questions.

At 5:40 p.m., the committee adjourned to the call of the Chair.

*ATTEST:*

La présidente fait une déclaration.

Peter Ryan fait une déclaration.

Alex Schadenberg fait une déclaration.

Jacki Jeffs fait une déclaration.

Mark Cameron et le Dr Joseph Ayoub font chacun une déclaration.

James Mahoney fait une déclaration.

Le sénateur Corbin fait une déclaration concernant sa position relativement à la recommandation de 1995 portant sur la création d'une troisième catégorie de meurtre.

Les témoins répondent aux questions.

À 17 h 40, le comité suspend ses travaux jusqu'à nouvelle convocation de la présidence.

*ATTESTÉ:*

*La greffière du comité,*

Heather Lank

*Clerk of the Subcommittee*



## EVIDENCE

OTTAWA, Monday, March 20, 2000

The Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 2:00 p.m. to examine the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death."

**Senator Sharon Carstairs** (*Chairman*) in the Chair.

[*English*]

**The Chairman:** Today is our sixth day of hearings under our mandate to update the unanimous recommendations of the 1995 Special Senate Committee report on Euthanasia and Assisted Suicide entitled "Of Life and Death". I would remind honourable senators and, most particularly, the witnesses, that this committee is not reopening the debate on assisted suicide and euthanasia. It is dealing strictly with the areas of the report where the original committee made unanimous recommendations. I would ask that everyone bear that in mind as we proceed through the hearings.

Before us today we have three panels. Our first panel is from the Department of Health Canada. We have Carole Bouchard, Manager, Office of Controlled Substances, Therapeutic Products Programme, and Dr. Brian Gillespie, Senior Medical Advisor, Bureau of Pharmaceutical Assessment.

**Ms Carole Bouchard, Manager, Office of Controlled Substances, Therapeutic Products Programme, Health Canada:** Madam Chair and committee members, I should like to take a few minutes to thank you for inviting staff of the Therapeutic Products Programme to speak with you today. We understand that you have some questions. However, before my colleague Dr. Brian Gillespie and I answer them, I would appreciate your offer to spend a few minutes to provide information to you on the drug review process under the Food and Drugs Act and regulations and on the regime utilized under the Controlled Drugs and Substances Act and its regulations to ensure accountability of those handling drugs with a known or high risk of abuse or misuse. We will touch on the international legislative framework and explain how patients are able to obtain these drugs to treat a medical condition.

Health Canada's Therapeutic Products Programme is the national authority that regulates, evaluates and monitors the safety, effectiveness, and quality of all therapeutic products available to Canadians. That includes drugs, medical devices, blood, tissues, organs, disinfectants and sanitizers. Drugs include pharmaceuticals and biologically derived products, both prescription and self-care products.

To market a drug in Canada, the manufacturer must demonstrate the effectiveness, safety and quality of the drug product and provide that information to the Therapeutic Products Programme in the form of a drug submission. That may include providing the results of laboratory work, animal studies and

## TÉMOIGNAGES

OTTAWA, le lundi 20 mars 2000

Le sous-comité de mise à jour de «De la vie et de la mort» du comité sénatorial permanent des affaires sociales, des sciences et de la technologie, se réunit aujourd'hui à 14 heures pour l'étude des faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé «De la vie et de la mort.»

**Le sénateur Sharon Carstairs** (*présidente*) occupe le fauteuil.

[*Traduction*]

**La présidente:** C'est aujourd'hui le sixième jour d'audience dans le cadre de notre mandat visant à mettre à jour les recommandations unanimes du rapport de 1995 du Comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé «De la vie et de la mort.» Je rappelle aux honorables sénateurs et surtout aux témoins que notre comité ne vise pas à relancer le débat sur l'aide au suicide et l'euthanasie. Son étude porte exclusivement sur les questions au sujet desquelles le comité initial a formulé des recommandations unanimes. Je vous demanderais de ne pas l'oublier au cours de nos discussions.

Nous entendrons aujourd'hui trois groupes de témoins. Le premier groupe se compose de fonctionnaires du ministère de la Santé. Il y a Carole Bouchard, gestionnaire, Bureau des substances contrôlées, Programme des produits thérapeutiques, et le Dr Brian Gillespie, conseiller médical spécial, Bureau de l'évaluation des produits pharmaceutiques.

**Mme Carole Bouchard, gestionnaire, Bureau des substances contrôlées, Programme des produits thérapeutiques, Santé Canada:** Madame la présidente et mesdames et messieurs les membres du comité, j'aimerais tout d'abord vous remercier d'avoir invité le personnel du Programme des produits thérapeutiques à vous parler aujourd'hui. Je me rends compte que vous voulez nous poser des questions, mais avant que mon collègue, le Dr Brian Gillespie, et moi-même y répondions, j'aimerais vous dire un mot sur le processus d'examen des médicaments prévu dans la Loi sur les aliments et drogues et son règlement et sur le régime mis en place en vertu de la loi réglementant certaines drogues et autres substances et son règlement, pour assurer l'imputabilité de ceux qui manutentionnent des substances qui risquent de faire l'objet d'abus. Nous parlerons brièvement de la législation internationale et expliquerons comment les malades peuvent obtenir ces substances pour se soigner.

Le Programme des produits thérapeutiques de Santé Canada est l'organisme national qui réglemente, évalue et contrôle l'innocuité, l'efficacité et la qualité de tous les produits thérapeutiques vendus aux Canadiens. Par produits thérapeutiques, on entend les médicaments, les matériels médicaux, le sang, les tissus, les organes, les désinfectants et les produits assainissants. Par médicaments, on comprend tant ceux vendus sur ordonnance que ceux en vente libre et les produits biologiques en font partie.

Pour vendre un médicament au Canada, le fabricant doit démontrer qu'il est sûr, efficace et de qualité et fournir cette information au Programme des produits thérapeutiques sous la forme d'un dossier de présentation. Ce dossier peut comprendre des résultats de laboratoire, d'études sur l'animal et d'essais

clinical trials. For example, in the case of a new active substance, that is, a substance that has not been previously marketed in Canada as a drug, the manufacturer must conduct a series of scientific trials, which must be accurately recorded and presented to TPP for review. The first pre-clinical phase, which includes laboratory work and animal studies, is intended to explore the drug's efficacy and safety before it is administered to humans. A large portion of possible drugs never makes it beyond that phase.

The next phase involves testing the drugs on humans, through clinical trials. These trials must be approved by ethics committees, and all clinical trial participants are informed about the nature and goals of the study, the potential risks and benefits, and their right to withdraw at any time. Once there is supporting evidence that a drug is both safe and effective, the manufacturer can then move toward the final stage of applying to have the drug approved for use in Canada.

The manufacturer is also required to provide details on the methods of manufacture and the controls that will be used to ensure that the quality of the drug is consistently maintained.

In order to provide information on the proper use of the drug, manufacturers must also submit a product monograph, which details the symptoms and side effects associated with use of the drug, as well as recommended dosages and administration; that document is carefully vetted by the scientists and doctors within the TPP.

The drug review process involves a methodological series of steps taken by scientists and physicians in the various bureaux in the Therapeutic Products Programme to assess all drugs before they are allowed onto the Canadian market. Often TPP will enlist the expertise of a large network of scientific professionals from other regulatory agencies, academia and private practice to aid in the review. The goal of the process is to provide Canadians with the latest in pharmaceutical technology, while adhering to the strictest of standards and ensuring that physicians and patients have as much information as possible on the safety and quality of the product.

If, at the conclusion of the review, the drug has been approved, the TPP issues a notice of compliance, or NOC, which indicates the drug's official approval in Canada, as well as a drug identification number, or DIN, which permits the manufacturer to market the drug in Canada.

No drug is approved without the full confidence of the TPP that the benefits of using the drugs outweigh the risks and that as much information as possible is being made available to Canadians on how to minimize the risks presented by the product.

cliniques. Par exemple, dans le cas d'une nouvelle substance active, c'est-à-dire une substance qui n'a pas encore été vendue au Canada en tant que substance médicamenteuse, le fabricant doit réaliser une série d'épreuves scientifiques qui doivent être soigneusement consignées dans des registres et présentées au PPT pour examen. La première phase, la phase préclinique, qui comprend des travaux en laboratoire et des études sur l'animal, vise à déterminer l'innocuité et l'efficacité de la substance avant qu'elle ne soit administrée à des humains. La majeure partie des médicaments potentiels ne réussit jamais à dépasser cette phase.

La phase suivante comprend l'administration de la substance à des humains dans le cadre d'essais cliniques. Ces essais doivent être approuvés par un comité d'éthique et tous les participants aux essais sont informés de la nature et des buts de l'étude, des risques et bénéfices potentiels et de leur droit de se retirer de l'étude en tout temps. Une fois qu'il a été démontré que la substance était sans danger et efficace, le fabricant peut passer au stade final, c'est-à-dire demander l'autorisation de mise en marché au Canada.

Le fabricant doit également fournir des renseignements détaillés sur la méthode de fabrication de la substance et sur les contrôles qu'il utilisera pour s'assurer que la qualité du produit est maintenue.

Afin de renseigner les utilisateurs sur l'usage approprié de la substance, le fabricant doit également soumettre une monographie thérapeutique exposant en détail les symptômes et les effets secondaires associés à l'utilisation de la substance, ainsi que les doses et le mode d'administration recommandés. Ce document est soigneusement examiné par des scientifiques et des médecins du PPT.

Le processus d'examen des médicaments comporte un ensemble méthodique d'étapes appliquées par les scientifiques et les médecins travaillant dans les divers bureaux du PPT en vue d'évaluer tous les médicaments avant qu'on autorise leur mise sur le marché. Le PPT fait souvent appel à un vaste réseau de spécialistes scientifiques d'autres organismes de réglementation, du milieu universitaire et de firmes du secteur privé pour obtenir de l'aide dans l'examen des médicaments. L'objectif du processus d'examen est de permettre aux Canadiens et aux Canadiennes d'avoir accès aux plus récents produits de la technologie pharmaceutique, tout en respectant les normes les plus strictes et en veillant à ce que les médecins et les patients aient le plus d'informations possible sur l'innocuité et la qualité du produit.

Si, à la fin de l'examen, la substance est approuvée, le PPT émet un avis de conformité pour indiquer que la substance est officiellement approuvée au Canada, et délivre un numéro d'identification (le DIN), qui permet au fabricant de vendre la substance au Canada.

Aucun médicament n'est approuvé sans que le PPT soit parfaitement convaincu que les avantages de son utilisation surpassent ses risques et que le plus d'informations possible soient communiquées aux Canadiens pour leur indiquer comment réduire au minimum les risques que présente le produit.



The TPP has set internationally competitive performance targets for its reviews. While the length of time for review depends on the product being submitted, generally the process for review of a unique drug takes an average of two years from the time that a manufacturer submits a "new drug submission" until the TPP approves the drug and issues the NOC. Throughout the process, the safety and well-being of Canadians is maintained as the paramount concern.

The TPP has been and continues to be committed to ensuring the greatest efficiencies in the drug review process. To do this, the TPP is pursuing several initiatives to streamline the process, including the capacity to receive and review electronic drug submissions; pursuing technical standards agreed to internationally; continuing negotiations with other countries, such as the United States, Japan, the European Union, Switzerland and Australia, on mutual recognition agreements that will help to expedite drug reviews in Canada when the submission is being reviewed by one of these other countries; and sharing reviews of drug submissions with other countries.

The TPP has a priority review process in place to expedite the review of promising drug products for life-threatening or severely debilitating conditions, such as AIDS or Parkinson's Disease, for which there are few effective therapies on the market.

Once a new drug is on the market, controls continue. The manufacturer must report any new information received concerning side effects, including failure on the part of the drug to produce the desired effect. In addition, the TPP monitors adverse reactions, investigates complaints and problem reports, maintains post-approval surveillance, and manages corrective action when necessary.

The evidence required and the process of review for drugs intended for pain control and sedation differ little from the process described above. The TPP monitors the standards of evidence and methods of demonstrating safety and efficacy used by other major regulatory agencies and those put forward by experts and professional societies in their appropriate areas of expertise. These standards are incorporated into the TPP's reviews. An important point to consider is that drugs used for pain control and sedation are used in a wide variety of clinical conditions, from control of acute pain of short duration, such as in post-traumatic or post-surgical events, to chronic pain control in terminally ill patients.

The decision as to which drugs to use and under what conditions falls within the scope of the practice of medicine. The regulation of the practice of medicine is the responsibility of the provinces through their Colleges of Physicians and Surgeons.

Les examens effectués par le PPT sont assujettis à des objectifs de rendement compétitifs sur le plan international. Bien que la durée de l'examen dépende du produit à l'étude, en règle générale, la durée d'examen d'une substance unique est en moyenne de deux ans à partir du moment où le fabricant soumet son dossier de présentation jusqu'au moment où le PPT donne son approbation et délivre un avis de conformité. Tout au long du processus d'examen, la sécurité et le bien-être de la population canadienne demeurent le centre de nos préoccupations.

Le PPT s'est engagé à rendre le processus d'examen le plus efficient possible. Pour ce faire, il a lancé plusieurs initiatives visant à rationaliser le processus, notamment la capacité de recevoir et de traiter des dossiers de présentation sous forme électronique; l'application de normes techniques reconnues à l'échelon international; la poursuite des négociations avec les États-Unis, le Japon, l'Union européenne, la Suisse et l'Australie sur des accords de reconnaissance mutuelle qui aideront à accélérer l'examen des médicaments au Canada lorsque le dossier de présentation est étudié par l'un de ces autres pays; le partage de l'examen des dossiers de présentation avec d'autres pays.

Le PPT s'est doté d'un processus de traitement prioritaire qui permet d'accélérer l'examen des substances prometteuses destinées à soigner des maladies très débilitantes ou qui menacent le pronostic vital, comme la maladie de Parkinson et le sida, pour lesquels il existe présentement sur le marché peu de traitements efficaces.

Une fois qu'un nouveau médicament est sur le marché, les contrôles se poursuivent. Le fabricant doit communiquer toute nouvelle information qu'il obtient concernant les effets secondaires fâcheux, y compris les informations indiquant que le médicament ne produit pas l'effet souhaité. En outre, le PPT surveille les réactions indésirables, enquête sur les plaintes et les problèmes signalés, maintient un système de pharmacovigilance et fait en sorte que des correctifs soient apportés au besoin.

Les preuves qui doivent être fournies et l'examen qui est effectué à l'égard des substances destinées à combattre la douleur ou à produire un effet sédatif diffèrent très peu du processus décrit ci-dessus. Le PPT surveille les normes de preuve et les méthodes de démonstration de l'innocuité et de l'efficacité utilisées par les autres grands organismes de réglementation et celles mises de l'avant par les experts et les corporations professionnelles dans leurs domaines d'expertise respectifs. Ces normes sont incorporées aux examens effectués par le PPT. Un point important à se rappeler est le fait que les médicaments utilisés pour produire des effets analgésiques et sédatifs servent à traiter un large éventail d'états cliniques, allant de la douleur aiguë de courte durée (c'est-à-dire, la douleur post-traumatique ou post-chirurgicale), au contrôle de la douleur chronique chez les patients en phase terminale.

La décision concernant le ou les médicaments à utiliser et pour quel état pathologique relève de l'exercice de la médecine. La réglementation de l'exercice de la médecine est du ressort des provinces, qui exercent cette responsabilité par l'entremise de leurs collèges de médecins et de chirurgiens.

I will now touch upon the international obligations for Canada.

The Canadian regulatory regime around controlled drugs derives principally from the direction given in the three United Nations drug conventions ratified by Canada. This Canadian regime is designed to keep the drugs within the legitimate medical supply system, ensuring that the legitimate medical and scientific needs of Canadians are met and ensuring the accountability of those handling the drugs. The result is that the regime utilized in Canada is similar to that used in other countries.

The regimes in some countries do not meet the convention requirements and some countries have not yet ratified all three international drug conventions. The United Nations, through its International Narcotics Control Board, is attempting to convince all countries to ratify and comply with the convention requirements because drug problems are not confined to one country, to one region of the world, or to one group of individuals.

The United Nations believes that all countries have a part to play in minimizing the availability, outside the legitimate medical and scientific system, of drugs that are subject to abuse and misuse. Thus, all countries must meet minimal standards of control and accountability, if that goal is to be achieved. The three international conventions control the manufacture, importing, exporting, and distribution of drugs, such as those used to alleviate pain, in a manner that permits them to be available to meet legitimate medical and scientific needs.

Most drugs used to alleviate pain are scheduled in these three UN conventions, and Canada, having ratified them, has an obligation to meet all of their requirements. Health Canada fulfils that obligation through the use of the Controlled Drugs and Substances Act and its regulations. Drugs such as morphine, codeine and heroin are subject to the provisions of the Single Convention on Narcotic Drugs, ratified and issued in 1961, and are listed also in Schedule I of the Controlled Drugs and Substances Act, as well as its narcotic control regulations.

Benzodiazepines and barbiturates, which are listed in the Convention on Psychotropic Substances issued in 1971, are in Schedules III and IV of the Controlled Drugs and Substances Act. Drug precursors used in illicit laboratories to produce a number of those drugs that are subject to abuse and misuse are listed in the United Nations Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances, which was issued in 1988. Those substances are scheduled under the Controlled Drugs and Substances Act in Schedules V and VI. It is expected that Canada's precursor regulations will be written in the very near future.

J'aimerais maintenant passer aux obligations internationales du Canada.

Le régime de réglementation du Canada pour les drogues contrôlées découle principalement de l'orientation fournie dans les trois conventions de l'ONU sur les drogues qui ont été ratifiées par le Canada. Ce régime canadien a été élaboré afin de maintenir les drogues dans un système légitime d'approvisionnement en médicaments de façon à répondre aux besoins médicaux et scientifiques légitimes des Canadiens et à veiller à la responsabilité des personnes qui manipulent ces drogues. Le régime utilisé au Canada est donc semblable à celui en place dans d'autres pays.

Toutefois, les régimes de certains pays ne répondent pas aux exigences des conventions et certains pays n'ont pas encore ratifié toutes les trois conventions internationales sur les drogues. L'Organisation des Nations Unies, par l'intermédiaire de l'Organe international de contrôle des stupéfiants, tente de convaincre tous les pays de ratifier les conventions et de se conformer à ses exigences puisque les problèmes liés aux drogues ne sont pas confinés à un pays, à une région du globe ou à un groupe de personnes.

L'Organisation des Nations Unies est d'avis que tous les pays ont un rôle à jouer dans la réduction, à l'extérieur des systèmes médicaux et scientifiques légitimes, de la disponibilité des drogues qui peuvent faire l'objet d'abus ou d'usage détourné. Pour atteindre cet objectif, tous les pays doivent donc satisfaire à des normes minimales en matière de contrôle et de responsabilité. Les trois conventions internationales contrôlent la fabrication, l'importation, l'exportation et la distribution des drogues, comme celles servant à atténuer la douleur, de façon à ce qu'elles soient disponibles pour répondre aux besoins médicaux et scientifiques légitimes.

Les trois conventions de l'ONU dressent la liste de la plupart des drogues servant à atténuer la douleur. Puisqu'il a ratifié ces conventions, le Canada doit se conformer à toutes les exigences qui y figurent. Santé Canada répond à ces exigences par l'application de la Loi réglementant certaines drogues et autres substances et du règlement pertinent. Les drogues comme la morphine, la codéine et l'héroïne sont assujetties aux dispositions de la Convention unique sur les stupéfiants de l'Organisation des Nations Unies, ratifiée en 1961, et figurent à l'annexe 1 de la Loi réglementant certaines drogues et autres substances du Canada et dans le Règlement sur les stupéfiants.

Visés par la Convention sur les substances psychotropes, adoptée en 1971, les benzodiazépines et les barbituriques figurent dans les annexes III et IV de la Loi réglementant certaines drogues et autres substances. Les précurseurs qu'utilisent les laboratoires clandestins pour produire un grand nombre des drogues pouvant faire l'objet d'abus ou d'usage détourné sont visés par la Convention des Nations Unies contre le trafic illicite des stupéfiants et des substances psychotropes adoptée en 1988. Ces précurseurs figurent dans les annexes V et VI de la Loi réglementant certaines drogues et autres substances. Le règlement canadien sur les précurseurs devrait être rédigé sous peu.



These conventions restrict the use of the scheduled drugs to medical and scientific use. While some are tabled as having no medical use, such as LSD, others can be prescribed by a licensed medical practitioner to treat a medical condition. All scheduled drugs require import-export controls, and those who manufacture, distribute, import or export them must be licensed.

Before drugs are added to the schedules of the international conventions, the World Health Organization provides medical and scientific advice on the appropriateness of such action. While that advice is not binding on those countries voting to add, delete or reschedule a drug under international control, it is provided to all countries and is seriously considered by those who are voting.

The Single Convention on Narcotic Drugs requires that some drugs, such as morphine, operate under an "estimate" scheme. Thus, each year the TPP provides the International Narcotics Control Board with Canada's estimated consumption and inventory of those drugs. A sufficient quantity of each of those drugs can then be imported to meet those consumption and inventory estimates for Canada. Should the estimate prove to be insufficient to meet our legitimate medical and scientific needs, it must be revised. Otherwise, there would be a shortage of the drug within Canada, because other countries are required to stop supplying a country once the estimate has been filled.

When the Controlled Drugs and Substances Act came into force in May of 1997, the Narcotic Control Act and Parts III and IV of the Food and Drugs Act were repealed. The Controlled Drugs and Substances Act has several sets of regulations, for narcotics, controlled drugs and restricted drugs, as well as a proposed set of regulations for targeted drugs. The latter set of regulations will include drugs such as the benzodiazepines. Also included are regulations for the commercialization of hemp, for the designation of analysts, and for police enforcement.

There is currently no production of controlled drug raw material in Canada. Canada imports all of its drug requirements. After receiving an import permit from the Therapeutics Products Programme, the licensed pharmaceutical company will import the raw drug material or, in some instances, the finished product. If it has received a notice of compliance from Health Canada, the manufacturer is able to sell the finished product to licensed distributors, pharmacists, hospitals, physicians, veterinarians, and dentists.

Health Canada also has a mandate to keep the international controlled drugs within the legitimate medical and scientific supply system permitted by the CDSA and its regulations. Those regulations permit inspectors authorized under the legislation to

Ces conventions limitent l'utilisation des drogues inscrites aux annexes à des fins médicales et scientifiques. Bien que certaines drogues soient désignées comme n'ayant aucune application médicale, par exemple le LSD, d'autres peuvent être prescrites par un praticien autorisé pour traiter un trouble médical. L'importation et l'exportation de toutes les drogues inscrites aux annexes font l'objet d'un contrôle. De plus, les fabricants, les distributeurs, les importateurs et les exportateurs de ces drogues doivent détenir un permis.

Avant que des drogues soient ajoutées aux annexes des conventions internationales, l'Organisation mondiale de la santé fournit les conseils médicaux et scientifiques sur la pertinence d'un tel ajout. Bien qu'ils n'aient pas force exécutoire pour les pays votant pour ajouter ou enlever une drogue assujettie à un contrôle international ou pour en modifier le contrôle, ces conseils sont fournis à tous les pays et pris sérieusement en considération par les pays qui votent.

La Convention unique sur les stupéfiants demande que certaines drogues, par exemple la morphine, fassent l'objet d'un mécanisme d'«estimation». Par conséquent, chaque année, le PPT fournit à l'Organe international de contrôle des stupéfiants des estimations de la consommation et des stocks de ces drogues pour le Canada. On peut alors importer une quantité suffisante de chacune de ces drogues en fonction de ces estimations. Si ces estimations s'avèrent insuffisantes pour répondre à nos besoins médicaux et scientifiques légitimes, elles doivent être revues. Si une telle revue n'était pas effectuée, il y aurait une pénurie de la drogue visée au Canada puisque les autres pays doivent arrêter d'approvisionner le Canada lorsque nos quantités estimées ont été atteintes.

Quand la Loi réglementant certaines drogues et autres substances est entrée en vigueur en mai 1997, la Loi sur les stupéfiants ainsi que la Partie III et la Partie IV de la Loi sur les aliments et drogues ont été abrogées. La Loi réglementant certaines drogues et autres substances prévoit certains règlements, dont celui sur les stupéfiants, celui sur les drogues contrôlées et celui sur les drogues d'usage restreint, de même qu'une série proposée de règlements sur les médicaments à cible définie. Cette dernière série de règlements comprendra des médicaments comme les benzodiazépines. Les règlements prévus sont des règlements pour la commercialisation du chanvre, la désignation des analystes et l'exécution policière.

À l'heure actuelle, il n'y a aucune production de matières premières pour les drogues contrôlées au Canada. Le Canada importe tous ses besoins à cet égard. Après avoir reçu un permis d'importation du Programme des produits thérapeutiques, une société de produits pharmaceutiques autorisée importera les matières premières pour les médicaments ou, dans certains cas, le produit fini. Si elle a reçu un avis de conformité de Santé Canada, elle peut vendre le produit fini à des distributeurs autorisés, des pharmaciens, des hôpitaux, des médecins, des vétérinaires et des dentistes.

Santé Canada a pour mandat de veiller à ce que ces drogues contrôlées à l'échelle internationale soient restreintes à l'approvisionnement médical et scientifique légitime autorisé en vertu de la Loi réglementant certaines drogues et autres substances

audit licensed dealers, pharmacies, hospitals, physicians, dentists, and veterinarians. The audits are undertaken to ensure drug accountability and to detect and investigate diversions. It is not the mandate of the TPP to regulate the professions of pharmacy, medicine, dentistry, or veterinary medicine. That is a provincial responsibility. However, the TPP communicates with the provincial licensing authorities when a health professional is part of the diversion and with the police when a criminal activity has taken place.

There are in Canada, as we mentioned, three normal avenues for physicians and patients to access the substances claiming medicinal value under the Food and Drugs Act and its regulations. Those three avenues are: when a drug has been approved for general marketing in Canada; when it is available to clinical trials; and when it is available through the Special Access Process, or SAP; and all of those are managed by the Therapeutic Products Programme within Health Canada. In all three cases, substances that are regulated under the Controlled Drugs and Substances Act may have to meet additional requirements, such as importation and distribution requirements.

After a notice of compliance has been issued to a drug company for a product, the company can make it available on the Canadian market. Products containing narcotics or controlled drugs can be prescribed by physicians, veterinarians and dentists licensed by a provincial licensing authority. The patient would then normally have the prescription filled at a local pharmacy. In a hospital, the physician prescribes a drug, and the hospital pharmacy usually supplies it for both in-patients and out-patients.

From time to time, a physician will read in the scientific literature that a certain drug is available in other countries and, from the information provided, feel that a patient would likely benefit, if he or she had access to the drug, because conventional therapies had failed or were inappropriate. However, if no NOC has been issued, no pharmacy will have the drug in stock, and, if the drug is scheduled under the Controlled Drugs and Substances Act, neither the physician nor the patient will legally be able to import it into Canada. The physician can, however, contact the Therapeutic Products Programme's Special Access Process. In those circumstances, the two areas of TPP — both the Special Access Process and the Office of Controlled Substances — will be involved. The staff will review the request and the Office of Controlled Substances will be required to make arrangements for such things as importation.

In conclusion, the TPP has a specific mandate to ensure that therapeutic drugs in Canada are safe, effective and of high quality. Furthermore, it manages a regime to ensure that those drugs that are internationally controlled are available for legitimate medical

et ses règlements. Ces règlements permettent aux inspecteurs autorisés en vertu de la loi d'effectuer des vérifications auprès des distributeurs autorisés, des pharmacies, des hôpitaux, des médecins, des dentistes et des vétérinaires. Ces vérifications sont entreprises afin de s'assurer que les intéressés rendent compte des médicaments et de déceler les détournements et d'enquêter sur ceux-ci. Le PPT n'a pas pour mandat de réglementer la profession de la pharmacie, de la médecine, de l'art dentaire ou de la médecine vétérinaire. Il s'agit là d'une responsabilité provinciale. Cependant, le PPT communique avec les organismes de réglementation professionnelles des provinces lorsqu'un professionnel de la santé est en cause dans le détournement, et avec le service de police lorsqu'il y a eu une activité criminelle.

Comme nous l'avons signalé, au Canada, il y a trois façons habituelles dont le médecin et le patient peuvent avoir accès à des substances pour lesquelles des allégations de valeur médicinale ont été faites en vertu de la Loi sur les aliments et drogues et son règlement, à savoir premièrement l'approbation d'une commercialisation générale, deuxièmement les essais cliniques et, troisièmement, le Programme d'accès spécial ou PAS; ces processus sont tous gérés par le Programme des produits thérapeutiques de Santé Canada. Dans ces trois cas, il se peut que les substances qui sont réglementées en vertu de la Loi réglementant certaines drogues et autres substances aient à satisfaire des exigences additionnelles comme des exigences en matière d'importation et de distribution.

Une fois l'avis de conformité délivré à la société de produits pharmaceutiques pour un produit donné, la société peut ensuite l'offrir sur le marché canadien. Les produits renfermant un stupéfiant ou une drogue contrôlée peuvent être prescrits par des médecins, des vétérinaires et des dentistes autorisés par un organisme de réglementation provincial. Normalement le patient ferait remplir l'ordonnance à une pharmacie locale. Dans un hôpital, le médecin prescrit un médicament et c'est habituellement la pharmacie de l'hôpital qui le fournit aux malades hospitalisés et aux malades en consultation externe.

Parfois, un médecin constatera en lisant la documentation scientifique qu'un certain médicament est offert dans un autre pays et, en s'inspirant de l'information fournie, estimera qu'un patient pourrait probablement en profiter s'il avait accès au médicament, et ce, en raison de l'échec ou du caractère inapproprié des thérapies conventionnelles. Puisqu'aucun AC n'a été délivré, les pharmacies ne l'auront pas en stock, et, lorsque le médicament est inscrit à l'Annexe de la Loi réglementant certaines drogues et autres substances, ni le médecin, ni le patient ne pourra légalement l'importer. Le médecin peut toutefois communiquer avec le Programme d'accès spécial du Programme des produits thérapeutiques. En pareilles circonstances, le PAS et le Bureau des substances contrôlées du PPT interviendront. Le personnel passera en revue la demande et le Bureau des substances contrôlées sera tenu de prendre des dispositions relativement à des éléments comme l'importation.

En guise de conclusion, le PPT a le mandat bien précis de veiller à ce que les produits thérapeutiques au Canada soient sûrs, efficaces et de haute qualité. Qui plus est, il gère un régime visant à s'assurer que les médicaments contrôlés à l'échelle



and scientific use while minimizing the diversion of those drugs to the illicit market.

We would like again to thank you for the opportunity of appearing before your committee. Doctor Gillespie and I are available to answer your questions.

**The Chairman:** Thank you. Before I turn to other senators, I have a couple of questions that I should like to ask that are more general in nature.

I understand that you have two major studies going on now. I do not know how you would categorize them under your system, but one is with respect to the use of heroin within the hospital setting and the other is with respect to the use of marijuana, which would also be within the hospital setting, but would as well, I understand, be outside the hospital setting. Can you give us any information about those two studies?

**Ms Bouchard:** If I may, I will start with the marijuana studies. As you are aware, a research plan was tabled by our Minister of Health last June; that plan includes various strategies and components of the research activities with respect to the use of marijuana for medical purposes. The three components of that plan are to undertake a research project with a group in Toronto, called the Community Research Initiatives of Toronto, along with the Canadian HIV Trial Networks. Those two groups, in association, will be conducting a research project on AIDS, or patients with HIV, with regard to trying to study the effects, for medical purposes, of marijuana on nausea and also as an appetite stimulant. That project has not been initiated; at this point patients have not been involved. However, they are in the process of finalizing their research protocol, which, as I mentioned in the presentation, will require regulatory approval and also ethical approval from the Canadian HIV Trials Network. We estimate that they may be in a situation where patients will be enrolled in a trial in the year 2000; so progress is being made.

The other component of the research plan is through the Medical Research Council. Researchers across the country have been invited to submit proposals for research activities or research projects with regard to marijuana. The date for submission of projects with the Medical Research Council was March 1, and we understood that some researchers had submitted a proposal for research projects. At this time, those projects are being reviewed within the Medical Research Council's overall structure. They are being looked at from the scientific perspective. We envisage that, through the Medical Research Council, we will have an interesting project in the field of marijuana for medical purposes, starting, we hope, in the year 2000.

Those are the two main components of the research plan with regard to activities that will lead to studying, specifically, marijuana for medical purposes. You have probably also heard that, through section 56 of the Controlled Drugs and Substances Act, some exemptions have been granted to patients to use marijuana for medical purposes. Those exemptions were granted following applications from those patients with support from their

internationale sont disponibles à des fins médicales et scientifiques légitimes, tout en réduisant au minimum le risque de détournement de ces médicaments vers le marché illicite.

Nous tenons une fois de plus à vous remercier de nous avoir donné l'occasion de nous présenter devant votre comité. Le Dr Brian Gillespie et moi serons heureux de répondre à vos questions.

**La présidente:** Merci. Avant de céder la parole aux autres sénateurs, j'aimerais vous poser une ou deux questions de nature générale.

J'ai cru comprendre que votre ministère avait lancé deux grandes études. Je ne sais pas comment vous les identifieriez dans le cadre de votre système, mais je sais que l'une d'entre elles porte sur l'usage de l'héroïne en milieu hospitalier, et l'autre sur l'usage de la marijuana, en milieu hospitalier et à l'extérieur, si j'ai bien compris, du milieu hospitalier. Pourriez-vous nous en dire un peu plus long sur ces deux études.

**Mme Bouchard:** Si vous le permettez, j'aimerais parler d'abord des études sur la marijuana. Comme vous le savez, un plan de recherche a été déposé par notre ministre de la Santé en juin dernier; ce plan inclut divers éléments et stratégies dans le domaine de la recherche sur l'usage de la marijuana pour des fins médicinales. Les trois éléments de ce plan sont: un projet de recherche avec un groupe de Toronto, le Community Research Initiatives, et le Réseau canadien d'essais sur le VIH. Ces deux groupes coordonneront un projet de recherche sur le sida, ou sur les patients atteints du VIH, afin d'étudier l'efficacité, à des fins médicinales, de la marijuana pour le traitement des nausées et de la perte d'appétit. Le projet n'a pas encore été lancé; les patients n'ont pas encore été recrutés. Cependant, ces deux organisations finalisent actuellement leur protocole de recherche qui, comme je l'ai mentionné dans mon exposé, nécessitera une approbation réglementaire et une approbation déontologique du Réseau canadien d'essais sur le VIH. Nous croyons que les patients commenceront à participer à des essais cliniques en l'an 2000; on progresse donc.

L'autre élément du plan de recherche est mis en oeuvre par le Conseil de recherches médicales. Un appel a été lancé à tous les chercheurs du pays pour les inviter à soumettre des propositions visant des activités ou des projets de recherche à l'égard de l'usage de la marijuana. La date limite pour la présentation de projets au Conseil de recherches médicales était le 1<sup>er</sup> mars, et nous avons appris que certains chercheurs avaient soumis une proposition de projets de recherche. Le Conseil de recherches médicales procède toujours à l'examen de ces demandes. On les étudie d'un point de vue scientifique. Nous prévoyons que grâce à cette activité du Conseil de recherches médicales, un projet intéressant de recherche sur l'usage de la marijuana pour des fins médicinales devrait être lancé en l'an 2000.

Il s'agit là des deux principaux éléments du plan de recherche sur l'usage de la marijuana pour des fins médicinales. Vous avez probablement également appris qu'en vertu de l'article 56 de la Loi réglementant certaines drogues et autres substances, certaines exemptions ont été accordées afin d'autoriser des patients à utiliser la marijuana à des fins médicinales. Ces exemptions ont été accordées à la suite de demandes présentées par des patients

physicians in those particular situations. Those are the three aspects of the elements of the research plan going on at this point.

With regard to heroin, we understand from TPP that some researchers are interested in developing clinical trials of the use of that substance in the treatment of people. I am not aware of any specific projects that have been initiated at this point, because we would have known with regard to the distribution of heroin, but again, people have been discussing the development of that type of research activity in Canada.

**The Chairman:** Then my information is not correct, because I understood there were some trials going on in some hospitals with respect to the use of heroin as opposed to morphine, or indeed in combination with some other drugs.

**Ms Bouchard:** You refer perhaps to the use of heroin in treatment for pain. Heroin is available in Canada. It was reintroduced to the Canadian market in 1985, and it is currently available for physicians to prescribe. The regulations specifically say that it is available for pain treatment, but it must be prescribed within the context of a hospital setting for in- or outpatients of the hospital.

You are totally right with regard to the availability of heroin in Canada for the treatment of pain. I was referring to some other researchers or clinicians in Canada who want to perhaps conduct some studies with heroin but for a different purpose than the treatment of pain.

**The Chairman:** My question was specifically with respect to pain treatment.

Dr. Gillespie, one issue that has been before this committee, and was before the previous committee, is the whole discussion of the titration of opiates and whether or not at some point the use of morphine or heroin kills the patient. Our palliative physicians consistently tell us that that is not the case. The body adjusts to the amount of the drug within the system, and it is highly unlikely that the use of those drugs actually leads to the death of the patient. Can you enlighten us on that? Do you have knowledge of any trials that have been conducted with respect to that?

**Dr. Brian Gillespie, Senior Medical Advisor, Bureau of Pharmaceutical Assessment, Health Canada:** I am unaware of any specific trials that have been conducted with respect to that aspect of the use of such drugs. We look at morphine in terms of its control of pain. There are recognized risk factors for using morphine. Individuals with cardiovascular disease or individuals with severe respiratory disease may be at increased risk. From my reading of the literature, I understand that individuals do become tolerant fairly rapidly when they are on these drugs and that the risk may be less than had been previously estimated. However, I have no specific knowledge, other than my reading of the literature.

**The Chairman:** Thank you.

[Translation]

dont les médecins appuyaient l'usage de cette substance dans des circonstances particulières. Il s'agit là des trois aspects du plan de recherche qui se déroule actuellement.

Pour ce qui est de l'héroïne, le PPT nous a appris que certains chercheurs seraient intéressés à lancer des essais cliniques pour l'usage de cette substance à des fins médicales. À ma connaissance, aucun projet n'a encore été lancé dans ce domaine, parce que nous aurions été mis au courant de la distribution d'héroïne; encore une fois, on discute actuellement au pays de ce genre de recherche.

**La présidente:** Les renseignements que j'avais obtenus ne sont donc pas exacts, parce qu'on m'avait dit que certains essais cliniques se déroulaient actuellement dans certains hôpitaux à l'égard de l'usage de l'héroïne par opposition à la morphine, ou de l'héroïne avec d'autres drogues.

**Mme Bouchard:** Vous parlez peut-être de l'usage de l'héroïne pour le traitement de la douleur. L'héroïne est disponible au Canada. Elle a été de nouveau introduite sur le marché canadien en 1985, et les médecins peuvent actuellement prescrire cette substance. Les règlements précisent que cette substance peut être utilisée pour le traitement de la douleur, mais elle doit être prescrite dans le contexte hospitalier, pour les patients hospitalisés ou pour les patients en clinique externe.

Vous avez tout à fait raison pour ce qui est de la disponibilité de l'héroïne au Canada pour le soulagement de la douleur. Je faisais allusion à d'autres chercheurs ou cliniciens au Canada qui souhaitent mener des études sur l'utilisation qui est faite de l'héroïne à des fins autres que celle du soulagement de la douleur.

**La présidente:** Ma question portait expressément sur le soulagement de la douleur.

Docteur Gillespie, l'une des questions sur laquelle le comité s'est penché et sur laquelle s'est aussi penché le comité précédent, c'est celle du dosage des opiacés. Nous nous sommes demandé si à un certain point on ne tue pas le patient en lui injectant de la morphine ou de l'héroïne. Les médecins qui pratiquent la médecine palliative nous ont dit que ce n'était pas le cas. Le corps s'adapte apparemment à la dose de médicaments qu'on lui administre et il est peu probable que le recours à ces médicaments entraîne la mort du patient. Quel est votre avis là-dessus? Savez-vous si des essais ont été menés dans ce domaine?

**Le docteur Brian Gillespie, conseiller médical principal, Bureau de l'évaluation des produits pharmaceutiques, Santé Canada:** Je ne connais pas d'essais qui ont été menés sur l'utilisation de ces drogues. Nous étudions dans quelle mesure la morphine permet d'atténuer la douleur. Son utilisation comporte certains risques. Les patients souffrant de maladies cardio-vasculaires ou de maladies respiratoires graves sont plus à risque. Les études que j'ai lues semblent indiquer que l'organisme tolère assez rapidement ces drogues et qu'elles présentent moins de risque pour la patient que ce qu'on croyait autrefois. Je ne peux cependant que me reporter aux études que j'ai lues.

**La présidente:** Je vous remercie.

[Français]



**Senator Beaudoin:** Canada controls all drug imports and exports. I suppose that there is very little variation with respect to this control from one country to another. What are these differences, if any, between our country and the countries around us, the United States or France, for example? Are they due primarily to the fact that we have different legislation or a different criminal code? To what extent do our statutes or our codes influence the import or export of drugs into Canada, again in the context of the palliative care that we are studying?

**Ms Bouchard:** Canada has signed the United Nations' international conventions, like most other countries. All of these countries, even the farthest away like Australia, follow the same rules, because the conventions covering the import or export of drugs all apply the same way. The International Narcotics Control Board is responsible for determining these rules.

For products that are often used to control pain, such as morphine or other strong substances, these countries must also respect the same system, which determines annual consumption amounts for each respective country in accordance with these conventions. Each country must establish its requirements for a one-year period, to ensure that sufficient products are imported to meet the population's needs.

Of course when we deal with sectors other than imports and exports, our national statutes come into play. Legislation can vary from one country to another in certain regards, but not really with respect to international conventions.

**Senator Beaudoin:** Are there major differences from one country to another with respect to pain management?

**Ms Bouchard:** Does your question refer to prescriptions, distribution or authorizations?

**Senator Beaudoin:** With respect to availability, is it easier here than elsewhere or the same? Are the same products used to manage pain?

**Ms Bouchard:** Without having done in-depth analyses, I would say that it is comparable. Countries import the raw materials they need to manufacture products to manage pain from accredited suppliers in the world. Opium, the basic ingredient for manufacturing most of these products, comes from countries that have the exclusive right to produce it.

Each country must assess its requirements in order to ensure that it responds to the population's needs.

**Senator Beaudoin:** Is there international control?

**Ms Bouchard:** Yes. If a country realizes that it has not adequately assessed its requirements, it is important to correct the evaluation as quickly as possible so that the country is not prevented from importing more. In Canada, we have never experienced a shortage. Requirements have always been adequately defined.

**Le sénateur Beaudoin:** Le Canada exerce un contrôle sur l'importation et l'exportation des drogues. Je suppose qu'il y a très peu de variantes quant à ce contrôle d'un pays à l'autre. En quoi consistent ces différences si elles existent entre notre pays et les autres qui nous entourent, les États-Unis ou la France, par exemple? Sont-elles dues au fait que nous ayons une législation ou un code pénal différents, entre autres? Dans quelles mesures nos lois ou nos codes peuvent-ils influencer l'importation ou l'exportation des drogues au Canada, toujours dans le contexte des soins palliatifs que nous étudions?

**Mme Bouchard:** Le Canada a accédé aux conventions internationales des Nations unies, comme la majorité des autres pays. Tous ces pays, même les plus éloignés tel que l'Australie, suivent les mêmes règles parce que les conventions s'appliquent toutes de la même façon en matière d'importation et d'exportation des drogues. L'Organe de contrôle international pour les stupéfiants est l'organisme chargé de déterminer ces règles.

Pour les produits souvent utilisés dans le traitement de la douleur, telle la morphine ou d'autres substances puissantes, ces pays doivent aussi respecter le même régime, lequel détermine les quantités de consommation annuelle respectives pour chacun des pays régis par ces conventions. Il revient à chaque pays d'établir ses besoins pour une période d'un an, afin de s'assurer qu'il ait suffisamment de produits importés nécessaires aux besoins de sa population.

Il est certain que lorsque nous touchons à d'autres secteurs autres que l'importation et l'exportation, cela concerne nos lois nationales qui, d'un pays à l'autre, peuvent varier sur certains points, mais pas vraiment en ce qui a trait aux conventions internationales.

**Le sénateur Beaudoin:** Y a-t-il des variantes importantes d'un pays à l'autre quant au soulagement de la douleur?

**Mme Bouchard:** Votre question vise-t-elle la prescription, la distribution ou les autorisations?

**Le sénateur Beaudoin:** Sur le plan de la disponibilité, est-ce plus facile chez nous qu'ailleurs ou équivalent? Fait-on appel aux mêmes remèdes pour soulager la douleur?

**Mme Bouchard:** Sans avoir fait d'analyses approfondies, je dirais que c'est comparable. Les pays importent, de fournisseurs attirés dans le monde, les produits de base nécessaires à la fabrication de produits pour le traitement de la douleur. L'opium, ingrédient de base à la fabrication de la plupart de ces produits, provient de pays qui détiennent l'exclusivité de sa production.

Chaque pays doit bien évaluer ses besoins afin de s'assurer de répondre aux exigences de sa population.

**Le sénateur Beaudoin:** Y a-t-il un contrôle international?

**Mme Bouchard:** Oui. Si un pays s'aperçoit qu'il n'a pas fait une évaluation adéquate de ses besoins, il est important de corriger rapidement cette évaluation pour ne pas empêcher l'importation. Au Canada, on n'a pas eu d'expériences de manque d'approvisionnement. Les besoins ont été adéquatement définis.

**Senator Corbin:** On page 2 of your presentation, in the first paragraph, you talk about testing the drugs on humans, through clinical trials. You say that these trials must be approved by ethics committees, and all clinical trial participants are informed about the nature and goals of the study, the potential risks and benefits, and their right to withdraw at any time. Why does this clause mention the right to withdraw at any time? Are there problems on that level? Have there been cases where people have withdrawn from clinical trials, and why?

[English]

**Dr. Gillespie:** I am unaware of any specific cases where individuals have withdrawn from criminal trials.

As with any medical treatment, including the approved use of drugs, an individual has the right to refuse treatment at any time. Perhaps they have had an adverse experience or feel uncomfortable continuing in a clinical trial. Clinical trials are conducted with experimental drugs, and patients generally have limited information as to both the drug's effectiveness and its safety. They may become uncomfortable about that and choose not to continue in the trial.

[Translation]

**Senator Corbin:** When you talk about participants, you are essentially referring to patients, yes? You are not referring to members of the ethics committee or members of any other professional body? By participant, you mean the patients who are the subjects of the clinical trials? The text is not very clear.

**Le sénateur Corbin:** À la page 2 de votre présentation, au premier paragraphe, vous parlez d'administration de la substance à des humains dans le cadre d'essais cliniques. Vous dites que ces essais doivent être approuvés par un comité d'éthique et que tous les participants aux essais sont informés de la nature et des buts de l'étude, des risques et des bénéfices potentiels et de leur droit de se retirer de l'étude en tout temps. Pourquoi retrouvons-nous cette clause donnant le droit de se retirer de l'étude en tout temps? Y a-t-il des problèmes sur ce plan? Y a-t-il eu des cas où des personnes se sont retirées de ces essais cliniques et pour quelles raisons?

[Traduction]

**Dr Gillespie:** J'ignore s'il est déjà arrivé que des patients décident de ne plus participer à des essais cliniques.

Comme pour tout traitement médical, un patient peut refuser à tout moment qu'on lui administre des médicaments. Peut-être ces personnes ont-elles eu une réaction au médicament ou n'ont plus voulu participer aux essais cliniques pour d'autres raisons. Les essais cliniques portent habituellement sur des médicaments expérimentaux et les patients disposent de très peu d'information sur l'efficacité et l'innocuité de ces médicaments. Ils peuvent décider pour cette raison de cesser de participer aux essais.

[Français]

**Le sénateur Corbin:** Quand vous parlez de participants, vous faites référence essentiellement aux patients, n'est-ce-pas? Ce ne sont pas des membres de comités d'éthique ou d'autres membres d'un quelconque corps professionnel? Par participant, voulez-vous dire uniquement les patients qui sont les sujets de l'essai clinique? Le texte n'est pas très clair, en fait.

[English]

**Dr. Gillespie:** With regard to withdrawal from the clinical trials, it is up to the patient or the participants. The ethics committees are committees or boards that are usually set up within hospitals or other institutions to review the protocol of the trial in order to ensure that the rights of the patients are protected and that all known safety measures are instituted. They often have a monitoring element so that, if an unusual or previously unexpected safety issue is identified, that will then be communicated to the patients and in some cases may even stop the trial.

[Translation]

**Senator Corbin:** Is the code of ethics the same everywhere in Canada or is there a specific code that applies to these clinical trials? Is this a code that has been defined by the department or is it a general professional code?

[English]

**Dr. Gillespie:** While I am not an expert in this area, there are certainly ethical codes within Canada relating to the practice of medicine. There are also international codes, such as the Helsinki Convention, for the protection of patient rights.

The Department of Health does not have specific codes. However, we do review clinical trials before they are approved to ensure that the safety of the subjects are protected in the clinical trials and that they are adequately informed as to the potential risks and benefits of the drug that they are going to be using in the trial.

[Translation]

**Senator Corbin:** Ms Bouchard, on page 5 of your brief, in the section that deals with manufacturing, you said that there is no production of controlled drug raw materials in Canada. Why is this the case and what do you mean by raw material?

**Ms Bouchard:** Opium, which is the basic ingredient in the manufacturing of morphine, for example, is produced exclusively by certain countries. Countries therefore import this basic product from the manufacturing countries in order to produce their own medication. Canada and other countries, such as France, buy their basic products outside the country.

**Senator Corbin:** Does that not necessarily mean that Canada has a deficiency in terms of basic product production?

**Ms Bouchard:** Do you mean that we are lacking in basic products?

**Senator Corbin:** We could be manufacturing them ourselves instead of importing them.

[Traduction]

**Dr Gillespie:** C'est au patient ou aux participants de décider s'ils souhaitent cesser de participer à des essais cliniques. Les comités déontologiques sont des comités ou des conseils qui sont mis sur pied par les hôpitaux et les autres établissements de santé pour revoir le protocole sur lequel repose l'essai afin de veiller à ce que les droits des patients soient protégés et que toutes les mesures de sécurité connues soient prises. Ils exercent souvent une certaine surveillance sur l'essai et communiquent aux patients l'information pertinente au sujet des risques inhabituels que présente l'essai ou des nouveaux risques qui ont été cernés et ils peuvent aussi parfois mettre fin à l'essai si les risques cernés sont trop grands.

[Français]

**Le sénateur Corbin:** Est-ce que le code d'éthique est le même partout au Canada ou y a-t-il un code spécifique auquel doivent se conformer ces essais cliniques? Est-ce un code défini par le ministère ou un code professionnel général?

[Traduction]

**Dr Gillespie:** Je ne suis pas un spécialiste de cette question, mais il existe certes au Canada des codes d'éthique portant sur la pratique de la médecine. Il existe aussi des codes internationaux comme la Convention d'Helsinki qui visent à protéger les droits des patients.

Le ministère de la Santé n'a pas adopté de codes en particulier. Nous examinons cependant les essais cliniques avant de les approuver pour voir si la sécurité des patients est assurée et s'ils ont été adéquatement informés des risques et des avantages que présente le médicament qui leur sera administré.

[Français]

**Le sénateur Corbin:** Madame Bouchard, au chapitre de la fabrication, à la page 6 de votre mémoire, vous avez dit qu'il n'y avait aucune production de matières premières pour les drogues contrôlées au Canada. Comment cela se fait-il et qu'entendez-vous par matières premières?

**Mme Bouchard:** L'opium, ingrédient de base à la fabrication de la morphine, par exemple, est produit exclusivement par certains pays. Par conséquent, les pays importeront ce produit de base de ces pays fabricants pour confectionner leurs propres remèdes. Le Canada et d'autres pays comme la France se procurent leurs produits de base à l'extérieur de leur pays.

**Le sénateur Corbin:** Cela ne veut pas nécessairement dire que le Canada est déficient sur le plan de la production des produits de base?

**Mme Bouchard:** Voulez-vous dire que nous manquons de produits de base?

**Le sénateur Corbin:** C'est-à-dire que nous pourrions en fabriquer au lieu d'en importer.



[English]

**The Chairman:** In one of our recommendations on pain control and sedation practices, we addressed the issue of total sedation. We heard about two examples of total sedation. Dr. Keon spoke about the total sedation of a patient immediately following surgery, particularly very complicated cardiac surgery, in order that the patient be absolutely still for a period of time. We were also told, however, that there is as well the practice of using total sedation for a dying patient, because the pain is so severe that the only way it can be controlled is to totally sedate the patient so that in fact the patient is comatose.

One of the recommendations we made was that the federal government, in cooperation with the provinces and territories, undertake a study to determine the frequency and conditions under which total sedation in Canada is practised. Do you know if any such study has been undertaken?

**Ms Bouchard:** No.

**The Chairman:** Thank you for coming today. You have been most helpful in providing the information that we require.

Honourable senators, our next witness this afternoon is Mr. Hugh Scher, Chair of the Human Rights Committee of the Council of Canadians with Disabilities.

Welcome, Mr. Scher. I would ask you to come to the table now and make your presentation to us.

**Mr. Hugh Scher, Chair, Human Rights Committee, Council of Canadians with Disabilities:** Madam Chair, it is my pleasure to be here with you today on behalf of the Council of Canadians with Disabilities. I chair the Human Rights Committee and have done so for the last five years.

The council is an organization of organizations of people with disabilities. It has representation from member groups across the country. It is what we call a cross-disability organization, in that it represents people with all kinds of different disabilities including physical, developmental and mental disabilities. Its membership consists of a number of provincial and territorial organizations as well as national organizations that are more disability specific. We represent approximately 250,000 people with disabilities across the country.

As Chair of the Human Rights Committee, I bring to you my experience both as a constitutional lawyer by profession and as someone who has been involved with these issues for the last 10 years. The first subject I wish to talk about is the disability context within which I and other people with disabilities are living today. The point I am trying to make is that without a full understanding of that context, it is difficult to have a full and frank discussion of the issues you want to talk about, which are very important. Although there have been many gains in terms of accessing social life, I am referring to the fact that people with disabilities continue in large measure to be excluded members of

[Traduction]

**La présidente:** L'une de nos recommandations sur l'atténuation de la douleur et la sédation portait sur la question de la sédation totale. On nous a donné deux exemples de sédation totale. Le Dr. Keon a fait allusion à la sédation totale du patient qui vient de subir une intervention cardiaque très compliquée dans le but de faire en sorte que le patient soit complètement immobile pendant un certain temps. On nous a aussi dit qu'on a parfois recours à la sédation totale pour les mourants quand c'est la seule façon d'atténuer leur douleur. Le patient se retrouve alors dans un état comateux.

L'une des recommandations formulées proposait que le gouvernement fédéral, en collaboration avec les provinces et les territoires, entreprenne une étude pour déterminer la fréquence à laquelle la sédation complète est pratiquée au Canada et les conditions dans lesquelles elle s'effectue. Savez-vous si des études de ce genre ont été entreprises?

**Mme Bouchard:** Non.

**La présidente:** Je tiens à vous remercier d'être venue ici aujourd'hui. Vous nous avez été des plus utiles en nous fournissant l'information dont nous avons besoin.

Chers collègues, notre prochain témoin cet après-midi est M. Hugh Scher, président du Comité des droits de la personne du Conseil des Canadiens avec déficiences.

Nous vous souhaitons la bienvenue, monsieur Scher. Je vous demanderais de prendre place à la table et de nous présenter votre exposé.

**M. Hugh Scher, président, Comité des droits de la personne, Conseil des Canadiens avec déficiences:** Madame la présidente, je suis très heureux d'être ici aujourd'hui au nom du Conseil des Canadiens avec déficiences. Je préside le Comité des droits de la personne depuis les cinq dernières années.

Le Conseil est un regroupement d'organisations de personnes handicapées. Il compte des membres de groupes d'un peu partout au pays. Il s'agit d'une organisation qui représente des personnes ayant différents types de déficiences, y compris des troubles du développement et des déficiences physiques et mentales. Le Conseil parmi ses membres un certain nombre d'organisations provinciales et territoriales ainsi que des organisations nationales représentant des personnes ayant une déficience en particulier. Nous représentons environ 250 000 personnes handicapées de tout le pays.

En tant que président du Comité des droits de la personne, je vous apporte mon expérience tant à titre d'avocat constitutionnel que de personne qui s'occupe de ces questions depuis 10 ans. Le premier sujet dont j'aimerais vous parler, c'est le contexte entourant la déficience dans lequel moi-même et d'autres personnes handicapées vivons aujourd'hui. L'argument que j'essaie de faire valoir c'est que sans comprendre pleinement ce contexte, il est difficile d'avoir une discussion pleine et franche des questions dont vous voulez parler, qui sont très importantes. Bien que les personnes avec déficiences aient réalisé de nombreux progrès au niveau des rapports sociaux, il n'en reste pas moins



Canadian society. That is, perhaps, reflected best by our 60 per cent to 70 per cent unemployment rate.

In large measure, that exclusion from mainstream social life has marginalized people with disabilities within Canadian society. As a consequence, it has led to a negative perception about people with disabilities that stems from a history of exclusion and marginalization, including times when people with disabilities were in institutions and institutionalization was the norm of social policy in this country.

That context has had a tremendous impact on the lives of people with disabilities, particularly in respect of accessing health care services in this country and in respect of the decisions that are made concerning the treatment and non-treatment of people with disabilities. I will point out a couple of examples.

Terry is an 18-year old Alberta boy with Down's syndrome who required a lung transplant. Because he had Down's syndrome, the hospital board at the time applied a policy that said that, because of his disability, they were not prepared to grant a lung transplant. Because of the considerable concerns raised by Terry, his family and others, eventually the hospital changed its policy and granted him the medical procedure he needed. In Alberta, the response on the open-line shows, and generally across the province, was to the effect: "What are we wasting our tax dollars and health care resources on this for?" The perception was that to use our scarce health care dollars to assist a person with Down's syndrome in accessing the necessities of life was deemed to be not worthwhile.

I represent a client in Ontario who has multiple sclerosis. He is 35-years old, bedridden and cannot speak. He communicates only by blinking. He requires a 24-hour-a-day oxygen service. A policy of the Ontario government is that the maximum it will pay for oxygen service is \$540 per month. My client's oxygen needs cost \$2,500 per month. Despite the fact that he is living in the community and that his wife is serving as his primary caregiver, and despite his clearly stated willingness to live, he is being told by the government and by the oxygen company that he now has to pay for his oxygen service and that, if he cannot, he should perhaps go to the hospital. That will not only cost our taxpayers thousands of dollars more, but will likely kill my client.

That is the context within which many people with disabilities are living today and trying to access health care services that are necessary for life. Very often when they request them they are shunned or questioned as to whether their lives are worthwhile.

Why is it that, when people with disabilities go in for a tonsillectomy, one of the first questions they are asked is whether they want a "do not resuscitate" order put on their chart. As I

qu'elles continuent dans une grande mesure à être exclues de la société canadienne, comme en témoigne notre taux de chômage de 60 à 70 p. 100.

Dans une grande mesure, cette exclusion de la vie sociale ordinaire a marginalisé les personnes avec déficiences au sein de la société canadienne. Par conséquent, cela a entraîné une perception négative de ces personnes qui découle d'une tradition d'exclusion et de marginalisation, sans compter l'époque où les personnes avec déficiences étaient placées en établissement et où le placement en établissement était la norme de la politique sociale dans ce pays.

Ce contexte a eu de terribles répercussions sur la vie des personnes avec déficiences, surtout en ce qui concerne l'accès aux soins de santé dans ce pays et en ce qui concerne les décisions prises concernant le traitement et le non-traitement des personnes avec déficiences. Je vais vous en citer quelques exemples.

Terry est un jeune Albertain de 18 ans qui a le syndrome de Down et qui avait besoin d'une transplantation de poumon. Comme il avait le syndrome de Down, le conseil d'administration de l'hôpital à l'époque a appliqué une politique voulant que, en raison de son handicap, il n'était pas disposé à lui accorder une transplantation de poumon. En raison des vives préoccupations exprimées par Terry, sa famille et d'autres personnes, l'hôpital a fini par changer sa politique et lui a accordé la procédure médicale dont il avait besoin. En Alberta, la réaction dans les émissions de la ligne ouverte et dans l'ensemble de la province en général était la suivante: «Pourquoi gaspillons-nous l'argent du contribuable et les ressources de la santé à ce genre de choses?» On considérait qu'il ne valait pas la peine d'utiliser les rares ressources de notre système de santé pour permettre à une personne ayant le syndrome de Down d'avoir accès aux choses essentielles de la vie.

Je représente un client en Ontario qui a la sclérose en plaques. Il a 35 ans, il est cloué au lit et il ne peut pas parler. Il communique uniquement en clignant des yeux. Il a besoin d'un service d'oxygène 24 heures par jour. Selon une politique du gouvernement ontarien, le maximum qu'il paiera pour le service d'oxygène est 540 \$ par mois. Les besoins en oxygène de mon client s'élèvent à 2 500 \$ par mois. Malgré le fait qu'il vit dans la collectivité et que son épouse est celle qui s'occupe principalement de lui, et malgré sa volonté clairement exprimée de vivre, le gouvernement et la société qui lui assure le service d'oxygène sont en train de lui dire qu'il doit maintenant payer pour ce service et que s'il ne le peut pas, il devrait peut-être aller à l'hôpital. Cela coûtera non seulement aux contribuables des milliers de dollars de plus, mais risque fort probablement de tuer mon client.

Voilà le contexte dans lequel vivent de nombreuses personnes avec déficiences aujourd'hui lorsqu'elles tâchent d'avoir accès aux services de santé qui sont nécessaires à la vie. Très souvent, lorsqu'elles demandent ces services, on les repousse ou on met en doute la valeur de leur vie.

C'est la raison pour laquelle, lorsque des personnes avec déficiences vont se faire enlever les amygdales, l'une des premières questions qu'on leur pose c'est si elles veulent qu'on

understand it, that is not common practice for most patients going in for tonsillectomies.

In spite of some of the gains we have made, and in spite of rulings by the Supreme Court of Canada, many people with disabilities still do not have access to the supports that are necessary for life and for the provision of appropriate care. In the case of *Eldrige*, who sued the Ministry of Health of the Government of British Columbia, the Supreme Court ruled that persons with disabilities are entitled to access health care services with the assistance of sign language interpretation, for example. That case involved a deaf woman who was having a baby. The Supreme Court of Canada said that that is an integral part of the service delivery of health care in the Province of British Columbia.

That is the context within which the discussion we are having today is taking place. It is a context of public acceptance or indifference, very often to serious abuse or to the killing of people with disabilities. I will talk about the *Latimer* case in a moment.

The purpose of our criminal law is to provide protection for society, including protection from murder. The purpose of our criminal law and our criminal sentencing process is to ensure stability, certainty, public safety, and equal treatment and benefit of the law to all Canadians. Punishment, deterrence, both general and specific, retribution, denunciation, and rehabilitation are all aspects of our criminal sentencing regime, and I will not go into them in great depth, but those are the relevant principles that are typically applied.

With respect to the crime of murder in this country, we have a history of mandatory minimum sentences. That history stems from an even further history, which held that murder in this country was punishable by capital punishment. Therefore, if you killed someone, your life would be taken. A compromise reached by our Parliament at a certain time in our history was to remove capital punishment as a means of meting out justice and to replace that process with what was deemed to be a more civilized process of mandatory minimum sentences. In the case of first degree murder, the mandatory sentence was life imprisonment without parole for 25 years; in the case of second degree murder, the mandatory sentence was life imprisonment without eligibility for parole for 10 years. That is the regime that continues to exist today.

Our organization has done some work on researching the charging practices and sentencing applications in this country. Let me talk generally about the two fundamental principles that are applied in determining when a charge will be prosecuted against someone. A Crown attorney particularly looks at whether there is a sufficiency of evidence so as to demonstrate a likelihood of conviction if all the facts of the case are proven and the case is brought to trial. The second factor that is looked at is whether or

inscrive une ordonnance de non-réanimation sur leur dossier. D'après ce que je crois comprendre, ce n'est pas une pratique courante pour la plupart des patients qui vont se faire enlever les amygdales.

Malgré certains des progrès que nous avons réalisés, et malgré certaines décisions de la Cour suprême du Canada, de nombreuses personnes avec déficiences n'ont toujours pas accès au soutien nécessaire à la vie et à la fourniture de soins appropriés. Dans l'affaire *Eldrige*, qui a poursuivi le ministère de la Santé du gouvernement de la Colombie-Britannique, la Cour suprême a déclaré que les personnes avec déficiences ont droit à l'accès aux services de soins de santé avec l'aide d'interprétation gestuelle, par exemple. Il s'agissait d'une femme sourde qui allait avoir un bébé. La Cour suprême du Canada a déclaré que cela fait partie intégrante de la prestation de services de soins de santé en Colombie-Britannique.

C'est donc le contexte dans lequel se déroulent les discussions d'aujourd'hui. C'est un contexte d'acceptation ou d'indifférence de la part du public, très souvent face à de mauvais traitements graves réservés aux personnes avec déficiences ou à la suppression de la vie de personnes avec déficiences. Je parlerai de l'affaire *Latimer* dans un instant.

Notre droit criminel vise à protéger la société, et à la protéger aussi contre le meurtre. Notre droit criminel et notre processus de détermination de la peine au criminel visent à assurer la stabilité, la certitude, la sécurité publique et à faire en sorte que tous les Canadiens jouissent d'un traitement égal et d'une protection égale de la loi. Les sanctions, la dissuasion, tant générale que particulière, le châtement, l'exemplarité de la peine et la réadaptation sont autant d'aspects de notre système pénal de détermination de la peine, et je ne les aborderai pas de façon approfondie, mais il s'agit des principes pertinents appliqués normalement.

En ce qui concerne le crime de meurtre dans ce pays, nous avons une tradition de peines minimales obligatoires. Cette tradition découle d'une tradition encore plus reculée voulant que le meurtre dans ce pays entraînait la peine de mort. Par conséquent, si vous tuez quelqu'un, on vous enlèvera la vie. À une certaine époque de notre histoire, notre Parlement a consenti à un compromis en éliminant la peine de mort comme moyen de rendre la justice et en la remplaçant par un processus considéré plus civilisé, à savoir les peines minimales obligatoires. Dans le cas de meurtre au premier degré, la peine obligatoire était l'emprisonnement à vie sans possibilité de libération conditionnelle pendant 25 ans; dans le cas de meurtre au deuxième degré, la peine obligatoire était l'emprisonnement à vie sans possibilité de libération conditionnelle pendant 10 ans. C'est le système qui existe toujours aujourd'hui.

Notre organisation a fait certaines recherches sur les méthodes de mise en accusation et les peines infligées dans ce pays. Permettez-moi de parler de façon générale des deux principes fondamentaux appliqués pour déterminer si la preuve est suffisante pour établir la probabilité d'une condamnation si tous les faits de l'affaire sont établis et que l'affaire est portée devant les tribunaux. Le deuxième facteur qui est examiné consiste à déterminer s'il est dans l'intérêt public d'intenter des poursuites



not prosecuting an offence is in the public interest, and it is in that area that I will spend a little more time, because I think it raises issues relevant to your deliberations today and in the future.

Some of the public-interest considerations applied across the country are: the serious nature of the allegation; whether a conviction is likely to result in a significant sentence; whether considerable harm was caused to the victim of the crime; and whether there was use or threatened use of a weapon. Whether the victim is a "vulnerable" person is a factor that is looked at as a matter of determining public interest in the prosecution of crimes in this country. Whether the accused had a previous criminal record is sometimes looked at, and whether the accused was in a position of trust or authority over his victim is also taken into consideration. Other factors taken into account are the accused's degree of culpability in relation to others who may have committed the crime with him; evidence of premeditation; and whether the offence was motivated by the victim's race, colour, religion, sex, age, sexual orientation, political beliefs or disability.

Our public office has recognized that disability, in and of itself, is a factor that one looks at in considering public interest in pursuing criminal prosecutions in this country. However, many provinces have expressly indicated that prosecutors should not look at, and indeed have prohibited them from looking at, a number of factors. These include things like race, religion, sexual orientation and political beliefs of the accused. Very often in many provinces the Crown is prohibited from even considering his or her own personal views or opinions with respect to the accused or the victim; hence, the notion that "Justice is blind".

It is important that we consider the impact of differentiating between murders motivated by compassion and other murders. It is particularly important that we look at the dangers of applying sentences based on the situation or circumstances of a victim, particularly where our view of that victim may be shaped by devaluing perceptions and understandings about that victim's quality of life that are prevalent in the context I have described to you today with respect to people with disabilities and assessing quality of life of people with disabilities in Canada.

The recommendation of this committee was that there be a third category of murder carved out with respect to murders that are motivated by compassion or mercy. My response, and my organization's response, to that is that it is extremely dangerous to begin differentiating between these kinds of crimes, because we are certain to be shaped in our perceptions by the context in which we live and the biases we hold. In our view, it is inevitable that those biases and negative perceptions will shape our decisions in ways that put at risk people with disabilities and other vulnerable Canadians.

If this committee is interested in considering changing or adapting the mandatory minimum sentences in this country, I and our organization would urge very strongly against creating a

dans le cas d'une infraction, et c'est sur cet aspect que j'aimerais m'attarder un peu plus car j'estime qu'il soulève des questions pertinentes dans le cadre de vos délibérations aujourd'hui et par la suite.

Voici certains des facteurs d'intérêt public appliqués partout au pays: le caractère grave de l'allégation; la probabilité qu'une condamnation entraînera une peine importante; le tort considérable causé à la victime du crime; et l'utilisation ou la menace d'utilisation d'une arme. Le caractère «vulnérable» de la victime est un facteur qui est examiné pour déterminer l'intérêt public dans le cadre de poursuites intentées relativement à un crime dans ce pays. Parfois on examine si l'accusé avait un casier judiciaire et aussi si l'accusé était en situation de confiance ou d'autorité vis-à-vis de sa victime. Parmi les autres facteurs dont on tient compte, citons le degré de culpabilité de l'accusé comparativement aux autres qui ont peut-être commis le crime avec lui; la preuve qu'il y a eu préméditation; et le fait que l'infraction a été motivée par la race, la couleur, la religion, le sexe, l'âge, l'orientation sexuelle, les convictions politiques ou la déficience de la victime.

Notre administration publique a reconnu que la déficience est en soi un facteur dont on doit tenir compte pour déterminer s'il est dans l'intérêt public d'intenter des poursuites au criminel dans ce pays. Cependant, de nombreuses provinces ont expressément indiqué que les procureurs ne devraient pas tenir compte d'un certain nombre de facteurs et le leur ont même interdit. Il s'agit entre autres de la race, de la religion, de l'orientation sexuelle et des convictions politiques de l'accusé. Très souvent dans de nombreuses provinces, la Couronne ne doit pas tenir compte de ses propres opinions concernant l'accusé ou la victime; d'où la notion selon laquelle la justice est aveugle.

Il est important d'examiner les conséquences qu'entraîne le fait de distinguer les meurtres motivés par la compassion d'autres meurtres. Il est particulièrement important d'examiner les risques d'appliquer des peines en fonction de la situation ou des circonstances d'une victime, surtout lorsque notre opinion de cette victime peut être influencée par une mauvaise perception et une mauvaise compréhension de la qualité de vie de la victime, attitudes d'ailleurs répandues dans le contexte que je vous ai décrit aujourd'hui en ce qui concerne les personnes avec déficiences et la façon dont on évalue la qualité de vie de ces mêmes personnes au Canada.

Votre comité a recommandé que l'on établisse une troisième catégorie de meurtre en ce qui concerne les meurtres motivés par la compassion ou la pitié. Ma réaction, et la réaction de mon organisation, c'est qu'il est extrêmement dangereux de commencer à faire une distinction entre ces types de crimes, parce que nous sommes sûrs de nous laisser influencer par le contexte dans lequel nous vivons et par les préjugés que nous avons. À notre avis, il est inévitable que ces préjugés et ces perceptions négatives influenceront nos décisions d'une manière telle qu'elle risque de mettre en danger les personnes avec déficiences et d'autres Canadiens vulnérables.

Si votre comité envisage de modifier ou d'adapter les peines minimales obligatoires dans ce pays, moi-même ainsi que notre organisation vous déconseillons très fortement de créer une

separate category of murder that would, in effect, amount to a category of the murder of vulnerable people.

When we look at murders that are motivated by compassion, the victims almost in every case are vulnerable people — people who are sick, people who are aged, people who have disability. If we are to craft a new crime of murder, which is really the murder of vulnerable people, then I think we must be very careful about looking at the implications of that, particularly for the community of people with disabilities, for the reasons I have stated, but also for all of us, because each of us at any point in time can become disabled. We will all age, and we will all become subject to the kinds of biases and perceptions that I have discussed here today. It is our council's recommendation that the murder provisions in place today remain as they are, because we view them as the last protection from serious abuse and violence for people with disabilities.

I find it intriguing that two years ago I was here talking to a Senate committee, and to the parliamentary justice committee, about a new offence that was being added to the Criminal Code relating to the sexual touching of people with disabilities as a specific crime. I recall that we and the committee were concerned about the fact that people with disabilities are disproportionately victimized in these kinds of crimes, and we acknowledged that disability is an aggravating factor that must be considered when we look at charging and sentencing one who is convicted of this kind of crime.

When we talk about murder, why do we not also look at disability as an aggravating factor? We are, in this discussion, looking at disability as a mitigating factor to justify the actions of a murderer, and I am concerned that that has the effect, intended or otherwise, of creating a third category of murder, the murder of vulnerable people.

If the committee were inclined to change mandatory minimum sentences, my recommendation would be that it not create a separate category of murder that would amount to the murder of vulnerable people, but that it apply the law equally to all Canadians and that it do away with mandatory minimum sentences. Therefore, all murderers would have applied to them the appropriate sentencing principles and would not be differentiated based on the nature of their crimes or, more particularly in my view, the circumstances of their victims.

I am not recommending that approach. Our council still believes that the murder provision represents a last safeguard to protect people with disabilities from serious abuse and death. I am recommending, if the committee is inclined to consider that approach, that it do so in a way that is applied equally to all Canadians and that does not single out people with disabilities and other vulnerable people, thus creating a category of killing that justifies the actions of killers who kill people with disabilities by taking away the significant punitive and deterrent effects of the Criminal Code sentencing provisions.

catégorie distincte de meurtre qui équivaldrait, en fait, à une catégorie de meurtre de personnes vulnérables.

Lorsque nous examinons les cas de meurtres motivés par la compassion, dans pratiquement chaque cas, les victimes sont des personnes vulnérables — des personnes malades, âgées, handicapées. Si nous envisageons d'établir une nouvelle catégorie de meurtre, qui équivaut ni plus ni moins au meurtre de personnes vulnérables, alors je pense que nous devons en examiner très soigneusement les répercussions, particulièrement pour les personnes avec déficiences, pour les raisons que j'ai énoncées, mais aussi pour chacun d'entre nous, car chacun d'entre nous peut devenir handicapé à tout moment. Nous vieillissons tous et nous finirons tous par faire l'objet des types de préjugés et de perceptions dont j'ai discuté ici aujourd'hui. Notre Conseil recommande que les dispositions relatives au meurtre en vigueur aujourd'hui restent telles quelles, parce que nous les considérons comme notre dernier recours pour protéger les personnes avec déficiences des mauvais traitements graves et de la violence.

Je trouve curieux qu'il y a deux ans je suis venu témoigner devant un comité sénatorial, et devant le comité parlementaire de la justice, à propos d'une nouvelle infraction qui était ajoutée au Code criminel et qui faisait du contact sexuel avec des personnes avec déficiences un crime particulier. Je me rappelle que notre organisation ainsi que le comité étaient préoccupés par le nombre disproportionné de personnes avec déficiences qui étaient victimes de ce type de crime. Et nous avions reconnu que la déficience est un facteur aggravant dont il faut tenir compte lorsque l'on accuse et on condamne une personne reconnue coupable de ce genre de crime.

Lorsque nous parlons de meurtre, pourquoi ne considérons-nous pas aussi la déficience comme un facteur aggravant? Dans la présente discussion, nous sommes en train d'envisager la déficience comme un facteur atténuant pour justifier les gestes d'un meurtrier, et je crains que cela ait pour résultat, délibéré ou autrement, de créer une troisième catégorie de meurtre de personnes vulnérables.

Si le comité envisage de modifier les peines minimales obligatoires, je recommanderais qu'il ne crée pas une catégorie distincte de meurtre qui équivaldrait au meurtre de personnes vulnérables, mais qu'il applique la loi également à tous les Canadiens et qu'il élimine les peines minimales obligatoires. Ainsi, on appliquerait à l'ensemble des meurtriers les principes appropriés de détermination de la peine sans distinction fondée sur la nature de leurs crimes, ni surtout à mon avis, les circonstances de leurs victimes.

Ce n'est pas ce que je recommande. Notre conseil demeure convaincu que les dispositions relatives au meurtre constituent une garantie pour protéger les personnes avec déficiences contre les sévices graves et la mort. Si le comité envisage cette solution, qu'il le fasse de façon à ce que cela s'applique également à tous les Canadiens et pas seulement aux personnes avec déficiences et aux autres personnes vulnérables, ce qui créerait une catégorie de meurtre justifiant les actes des meurtriers qui tuent des personnes avec déficiences en éliminant l'important effet punitif et dissuasif des dispositions du Code criminel concernant la détermination de la peine.



Do not deny the equal application and the benefit of the law to people with disabilities. To do so could potentially represent a significant violation of our Charter guarantees of equality under section 15 of the Charter of Rights and Freedoms.

Our concern in this area was prompted in large measure by a case that is well known to all of us here: I refer to the murder of Tracy Latimer. Our council was an intervenor in that case at both the Court of Appeal in Saskatchewan and the Supreme Court of Canada. It is the view of our council members that that case reflects the reality of attempting to trivialize or marginalize the actions of a killer who decided to, in a premeditated, planned and deliberate way, take his daughter, put her in the cab of his truck, gas her to death, lie about it to the police, cover it up and allow his wife to come home and find the girl dead in her bed and suggest that she had died in her sleep.

If the law is not applied, all people with disabilities are put at risk in what is more than just a hypothetical or theoretical debate at this time.

Years ago we spoke about how a slippery slope would be created and the flood gates would be opened if Robert Latimer were set free. Without influencing anything that the Supreme Court may or may not do, the fact is that the court's and the public's reaction to Robert Latimer has set in motion already a series of actions that have ended in the murder of children across this country — whether it is Antoine Blais in Quebec, an autistic child who was drowned by his mother in his bathtub at 12 years of age; Katie Lynn Baker, who was starved to death by her mother at age 4 in British Columbia; Ryan Wilkinson, who was, in the same manner as Tracy, gassed to death by his mother in a murder-suicide in Hamilton, Ontario; or the many others that we know about, or do not yet know about, or who have not yet been murdered but will be, if we do not as a society and as a Parliament take steps to ensure that our most vulnerable are protected and afforded the equal benefit and protection of our law, including our criminal law.

**Senator Beaudoin:** Actually, Mr. Scher, I do remember that when we discussed the *Latimer* case in committee we suggested a third degree of murder, and we gave some attention to that concept, but as it was nearly at the end of our work I do not think anything came of it.

It is true that this is a complex matter. I agree with you. On the other hand, we must take into account that it is still a murder; we all agree on that. Obviously, it is a murder. The question of whether it is a murder that is different from other murders — let us say murders by the Mafia — remains to be taken into account.

Do I understand that, in your opinion, we should not consider that possibility? The reason I ask you the question is that all murders are not necessarily the same. A murder by a member of the Mafia and a murder by a man like Latimer are not in the same category at all. However, they are both still murders.

My first reaction is to say that we must give some thought to this issue. You are the first witness, as far as I remember, to address exactly this problem. That is why I ask you this question.

Ne refusez pas la même application de la loi aux personnes avec déficiences. Cela risquerait de violer gravement la garantie d'égalité que nous confère l'article 15 de la Charte des droits et des libertés.

Nos inquiétudes à cet égard viennent en grande partie d'une affaire que tout le monde connaît bien ici, le meurtre de Tracy Latimer. Notre conseil est intervenu dans cette affaire devant la Cour d'appel de la Saskatchewan et la Cour suprême du Canada. Nos membres estiment que ce cas montre bien ce qui se passe lorsqu'on cherche à minimiser l'acte d'un meurtrier qui a décidé, de façon préméditée et délibérée, d'amener sa fille dans son camion et de l'asphyxier, de mentir à la police et de faire en sorte que sa femme trouve sa petite fille morte dans son lit à la maison en laissant croire qu'elle était morte pendant son sommeil.

Si la loi n'est pas appliquée, toutes les personnes avec déficiences sont mises en danger dans ce qui n'est pas seulement un débat purement hypothétique ou théorique.

Il y a quelques années, nous avons fait valoir que nous nous engagerions sur une pente glissante si Robert Latimer était libéré. Sans vouloir influencer la Cour suprême, le fait est que son jugement et la réaction du public vis-à-vis de Robert Latimer ont déjà entraîné une série d'actes qui se sont traduits par le meurtre d'enfants un peu partout au Canada, que ce soit celui d'Antoine Blais, au Québec, un enfant autiste que sa mère a noyé dans sa baignoire à l'âge de 12 ans, de Katie Lynn Baker, que sa mère a laissé mourir de faim à l'âge de quatre ans, en Colombie-Britannique, de Ryan Wilkinson, qui, comme Tracy, a été asphyxié par sa mère lors d'un meurtre suivi d'un suicide à Hamilton, en Ontario ou les nombreux autres cas que nous connaissons ou ne connaissons pas encore ou ceux qui n'ont pas encore été assassinés, mais qui le seront, si notre société et notre Parlement ne prennent pas des mesures pour protéger les plus vulnérables d'entre nous et leur accorder la même protection de la loi, y compris du droit pénal.

**Le sénateur Beaudoin:** En fait, monsieur Scher, je me souviens que, lorsque nous avons discuté de l'affaire *Latimer* en comité, nous avons suggéré de créer une troisième catégorie de meurtre, mais comme c'était près de la fin de nos travaux, je ne pense pas que cela ait débouché sur quoi que ce soit de concret.

Il s'agit certainement d'une question complexe. Je suis d'accord avec vous. D'un autre côté, il faut tenir compte du fait que c'est quand même un meurtre; nous sommes tous d'accord sur ce point. De toute évidence, c'est un meurtre. Il reste à voir si c'est un meurtre différent des autres meurtres, disons de ceux que commet la mafia.

Dois-je comprendre que, selon vous, nous ne devrions pas envisager cette possibilité? Je vous pose la question parce que tous les meurtres ne sont pas nécessairement semblables. Un meurtre commis par un membre de la mafia et un meurtre commis par un homme comme Latimer n'entrent pas du tout dans la même catégorie. Ce sont toutefois des meurtres dans les deux cas.

Ma première réaction est de dire que nous devons réfléchir à cette question. Si je me souviens bien, vous êtes le premier témoin qui aborde précisément ce problème. Voilà pourquoi je vous pose

It worries me to a certain extent, as it does my colleagues, I am sure. We wish to be quite sure that such a study is worthwhile and that we should do it. If you say it should be taken under further study, I may understand that. Do you say that we should not pay any attention to that possibility?

**Mr. Scher:** I would agree with you that not every murder is the same and that murders are different in nature by their very circumstances.

I do believe that the murder of Tracy Latimer is just like any other murder. This was a child who was significantly disabled, yes, but who, according to her own mother's journal entries, was in school the week before she was killed, had a dislocated hip and was scheduled for surgery the week after she was killed. That surgery, according to her doctor, would have significantly remedied her pain. Tracy had a father who had a very serious problem with medical technologies and with needles and was phobic, according to a psychiatrist. This man took it upon himself to play judge, jury and executioner with his daughter. Whether that was for what he believed were compassionate motives or not, he never took the stand to say. He was never subjected to cross-examination.

Your question is: Given that different murders are different in nature, does that justify a third category of murder? My answer is that, no, it does not. It does not, because what you would then be saying is that, yes, not all murders are equal, but all murders, except for this kind of murder, will be treated according to the existing mandatory requirements under the law. Where the victim is a vulnerable person, or a person with a disability, or at the end stages of life, then that murder will be treated differently and will be subject to a judicial discretion with respect to sentencing.

Do not create a third category called "murder of vulnerable people". If your concern, however, is that mandatory sentencing is a constitutional and a moral problem, then that is something you might wish to address. I am not suggesting that that is a good thing. I do not believe it is. However, it would be a more sensible and principled approach to address your concerns about the different nature of different crimes than it would be to set up a completely separate category of murder that, in essence, amounts to a de facto acceptance of euthanasia in some respects and, in other respects, the denial of the equal benefit and protection of law to a particular group of people.

Yes, murders are different. No murder is good. I understand you to be acknowledging that murder is not a good thing. What is at issue here is how you acknowledge it and how you sentence and punish for it. Do not create a separate category that will target, further exclude, and marginalize people with disabilities as victims. It is not necessary. A judge could use equal discretion in sentencing Paul Bernardo as he could in sentencing Robert Latimer.

**Senator Beaudoin:** I agree with you: a murder is a murder. As a jurist, I am against all murders, obviously. However, I have to

la question. Cela m'inquiète dans une certaine mesure, mais je suis certain que mes collègues partagent mon inquiétude. Nous voulons être certains que cette étude en vaut la peine et que nous devrions l'entreprendre. Si vous dites qu'un examen plus approfondi est nécessaire, je peux le comprendre. Dites-vous que nous ne devrions pas envisager cette possibilité?

**M. Scher:** Je suis d'accord avec vous pour dire que tous les meurtres ne sont pas semblables et que les meurtres sont de nature différente en raison des circonstances dans lesquelles ils sont commis.

Je crois que le meurtre de Tracy Latimer doit être considéré comme tout autre meurtre. C'était une enfant très handicapée, en effet, mais qui selon le journal tenu par sa propre mère, fréquentait l'école la semaine précédant son meurtre et devait se faire opérer pour une luxation de la hanche la semaine précédant le meurtre. Selon son médecin, cette intervention chirurgicale aurait nettement réduit sa douleur. Tracy avait un père qui était allergique aux technologies médicales, aux seringues et qui avait des phobies, selon un psychiatre. Cette homme s'est arrogé le rôle de juge, jury et bourreau vis-à-vis de sa fille. Il n'a jamais témoigné pour dire si c'était pour des motifs qu'il croyait humanitaires ou non. Il n'a jamais été soumis à un contre-interrogatoire.

Vous me demandez si, étant donné que la nature des meurtres diffère, cela justifie la création d'une troisième catégorie de meurtre? Ma réponse est non. Cela reviendrait à dire que tous les meurtres ne sont pas similaires, mais qu'à l'exception de ce genre de meurtre, tous les meurtres seront traités en fonction des exigences obligatoires de la loi. Lorsque la victime est une personne vulnérable ou souffrant d'une déficience ou encore une personne à la fin de sa vie, son meurtre sera traité différemment et les tribunaux auront toute latitude en ce qui concerne la détermination de la peine.

Ne créez pas une troisième catégorie pour les «meurtres de personnes vulnérables». Si vous pensez toutefois qu'une sentence obligatoire pose un problème du point de vue constitutionnel et moral, c'est une question que vous pourriez examiner. Je ne veux pas dire que ce soit une bonne chose. Je ne le crois pas. Il serait toutefois préférable que vous vous penchiez sur vos préoccupations quant à la nature différente des crimes que d'établir une catégorie de meurtre entière distincte qui reviendrait à accepter de facto l'euthanasie et à refuser les mêmes avantages et la même protection de la loi à un groupe de gens.

Oui, les meurtres sont différents. Le meurtre est toujours une mauvaise chose. Je sais que vous le reconnaissez. Il s'agit de voir comment vous allez le reconnaître et comment le punir. Ne créez pas de catégorie distincte qui va cibler et aussi exclure et marginaliser davantage les personnes handicapées. Ce n'est pas nécessaire. Un juge pourrait se servir des mêmes pouvoirs discrétionnaires pour condamner Paul Bernardo que pour condamner Robert Latimer.

**Le sénateur Beaudoin:** Je suis d'accord avec vous quant au fait qu'un meurtre est un meurtre. En tant que juriste, je suis



admit that the *mens rea* may differ from one case to another. As we say in French:

[Translation]

“No one should take the law into his own hands.”

[English]

I do not know how you say that in English, but it is, and should continue to be, a murder. We realize that one murder can be quite different from another. It may be premeditated or second-degree. The question is should we have a third-degree murder. I want to study that matter in more detail.

Something must be done about the sentencing. Obviously, Latimer is not in the same category as Bernardo. What do we do with a case like that? It is before the Supreme Court. I am sure we will study it in more detail.

You have said that, no, we should not do that, but do something else. We will try to find that something else.

**Mr. Scher:** To do what you are proposing in terms of third-degree murder is to do more harm than is necessary. I say that because you would be putting at risk a significant element of our population, which is not necessary. You can accomplish the same goal without targeting and putting at risk this element of the population, if that is what you choose to do. To take that approach and to single out this group of people as victims is the wrong approach and a very dangerous one.

**The Chairman:** Mr. Scher, in your presentation you made particular reference to the case of *Blais*. As you know, that woman was never charged with anything, which is the dilemma we face in our original hearings. I have to tell you that what we discovered was that the prosecutorial experience across the country was tremendously varied. Dr. Dellaroca, for example, was charged with murder and was convicted of issuing a noxious substance, when he had clearly given a substance that killed his patient. In my view, he should have been charged with murder. However, the prosecutors decided, for whatever reason, that, first, perhaps, they could not have gotten a conviction, which is why they kept reducing it, or, second, that they did not think the offence warranted a conviction for murder. We know that was the case in *Meyers* in Nova Scotia, where they did not charge with murder but with manslaughter. The individuals involved got off scot-free. I believe a suspended sentence was imposed; however, that was the extent of the punishment they received.

To be fair to the members of the committee, what we desired from this “murder three” was that through the use of murder three more people would be charged with murder rather than the contrary — that is, not charged with anything or with something that was so limited that there would not be any condemnation of the act that they performed. Would you comment on that, please?

contre tous les meurtres, bien entendu. Je dois toutefois reconnaître que l'intention criminelle peut différer d'un cas à l'autre. Comme nous le disons en français:

[Français]

“Personne ne doit se faire justice elle-même.”

[Traduction]

Je ne sais pas comment vous le dites en anglais, mais il s'agit d'un meurtre. Nous savons qu'un meurtre peut différer d'un autre. Il peut s'agir d'un meurtre avec préméditation ou d'un meurtre au deuxième degré. Je voudrais étudier la question plus en détail.

Il faut faire quelque chose au sujet de la peine qui est imposée. De toute évidence, Latimer n'est pas dans la même catégorie que Bernardo. Que faut-il faire dans un cas comme celui-là? La cause est devant la Cour suprême. Je suis sûr que nous allons l'étudier de façon plus détaillée.

Vous avez dit qu'il ne faut pas faire cela, mais faire autre chose. Nous allons essayer de déterminer ce que cette autre chose pourrait être.

**M. Scher:** Faire ce que vous proposez en créant une catégorie de meurtre au troisième degré ferait plus de tort que nécessaire. Je dis cela parce que vous vous trouveriez ainsi à mettre à risque une part importante de la population, et cela n'est pas nécessaire. Vous pouvez accomplir la même chose sans cibler cet élément de la population et le mettre à risque, si c'est ce que vous décidez de faire. La logique qui vous amènerait à isoler ce groupe de personnes parmi les victimes n'est pas celle qui convient et elle est même très dangereuse.

**La présidente:** Dans votre exposé, monsieur Scher, vous avez évoqué expressément l'affaire *Blais*. Comme vous le savez, cette dame-là n'a jamais été accusée de quoi que ce soit, ce qui cause justement le dilemme auquel nous nous sommes heurtés dans nos délibérations initiales. Je dois vous dire que nous avons constaté que l'expérience au niveau de la poursuite varie énormément dans les différentes régions du pays. Ainsi, le Dr Dellaroca a été accusé de meurtre et a été condamné pour avoir administré une substance nocive, alors qu'il avait clairement administré à son patient une substance qui l'a tué. À mon avis, on aurait dû l'accuser de meurtre. La poursuite a toutefois décidé, pour je ne sais trop quelle raison, ou bien qu'il aurait été impossible d'obtenir une condamnation, ce qui expliquerait qu'elle ait baissé à plusieurs reprises la gravité du chef d'accusation, ou bien que l'infraction ne méritait pas une condamnation pour meurtre. Nous savons que c'était là le cas dans l'affaire *Meyers*, en Nouvelle-Écosse, où la poursuite a porté une accusation, non pas de meurtre, mais d'homicide involontaire. Les inculpés s'en sont sortis complètement indemnes. Je crois qu'on leur a imposé une peine avec sursis; c'est là tout ce qu'ils ont reçu comme punition.

En toute justice envers les membres du comité, ce que nous voulions accomplir avec cette catégorie de meurtre au troisième degré, c'était qu'il y ait un plus grand nombre de personnes qui puissent être accusées de meurtre, plutôt que le contraire — c'est-à-dire, que ces personnes ne fassent l'objet d'aucune accusation ou que l'accusation soit tellement minime



**Mr. Scher:** I agree that that was the intention of the committee. I do not think I have said anything that disagrees with that. What I am saying is that you can do that, if you take away the mandatory minimum sentences for murder generally and subject all murderers to the same judicial discretion and sentencing and to the equal application of the law.

**Senator Beaudoin:** Did you say that we may solve this problem by removing the minimum sentences?

**Mr. Scher:** Yes, if what you are attempting to do is to make murder a more attractive charge so that prosecutors will feel more comfortable to use their discretion to charge murder in cases where it is warranted, but would be otherwise fearful of doing so because of a mandatory minimum. If you remove that minimum, you give the prosecutors the comfort to use that discretion to charge with and to prosecute for murder.

**Senator Beaudoin:** Let us suppose we remove the minimum sentence. Will discretion be used in its place?

**Mr. Scher:** Yes.

**Senator Beaudoin:** Are you saying it should be entirely discretion?

**Mr. Scher:** That is what you are suggesting for third-degree murder.

**Senator Beaudoin:** No, we do not suggest that. A murder is a murder.

**Mr. Scher:** However, with respect to sentencing, you are suggesting that for murder three, as I understand it, the trial judge would have exclusive discretion as to sentencing. There would not be limitations on that. In other words, if the judge said that under the circumstances two years less a day would be an appropriate sentence, he would be free to do that. If the judge felt that, under the particular circumstances, probation or time served were appropriate, he could do that. If you remove the mandatory minimum sentences, you enable judges to do the same thing, and you still ensure that everyone has the same law applied to them.

**Senator Beaudoin:** We should give further thought to that.

**Mr. Scher:** I will address one of the other points in terms of all murders being the same. I think we would agree as a matter of principle that someone who is dying of terminal cancer and will be dead within a period of minutes, hours or days is significantly different from a 12-year-old with cerebral palsy whose life expectancy is anywhere from one day to 70 or 80 years and who is a living and functioning person. Once again you have this issue of the circumstances.

que l'acte qu'elles auraient commis ne ferait l'objet d'aucune sanction véritable. Auriez-vous un commentaire à faire?

**M. Scher:** Je ne nie pas que c'était là l'intention du comité. Je ne crois pas avoir dit quoi que ce soit qui permette de penser le contraire. Ce que je dis, c'est que vous pouvez y arriver en supprimant les peines minimales obligatoires pour tous ceux qui sont reconnus coupables de meurtre, de façon qu'ils soient soumis à la même discrétion judiciaire, aux mêmes principes de détermination de la peine et à l'application égale de la loi.

**Le sénateur Beaudoin:** Avez-vous dit que nous pourrions régler le problème en éliminant les peines minimales?

**M. Scher:** Oui, si ce que vous cherchez à faire, c'est de rendre l'accusation de meurtre plus attrayante, afin que la poursuite se sente plus à l'aise d'user de son pouvoir discrétionnaire pour porter une accusation de meurtre dans les cas où une telle accusation serait justifiée mais où on hésiterait à y recourir à cause de l'existence d'une peine minimale. Si donc cette peine minimale était éliminée, la poursuite se sentirait plus à l'aise d'exercer sa discrétion pour porter une accusation de meurtre et chercher à obtenir une condamnation pour meurtre.

**Le sénateur Beaudoin:** Supposons qu'on élimine la peine minimale. Est-ce la discrétion qui viendrait la remplacer?

**M. Scher:** Oui.

**Le sénateur Beaudoin:** Dites-vous qu'il faudrait une discrétion sans aucune entrave?

**M. Scher:** C'est bien ce que vous proposez avec cette catégorie de meurtre au troisième degré.

**Le sénateur Beaudoin:** Non, ce n'est pas ce que nous proposons. Un meurtre, c'est un meurtre.

**M. Scher:** En ce qui a trait toutefois à la détermination de la peine, vous proposez que, dans le cas d'un meurtre au troisième degré, si j'ai bien compris, le juge de première instance aurait le pouvoir exclusif de déterminer la peine qui convient. Sa discrétion ne serait soumise à aucune limite. Autrement dit, si le juge trouvait que, dans les circonstances, une peine de deux ans moins un jour conviendrait, il serait libre d'imposer cette peine. S'il estimait que, dans les circonstances particulières, il conviendrait de condamner l'inculpé à une mise en liberté surveillée ou à un emprisonnement équivalant au temps qu'il aurait déjà passé en détention, il aurait cette discrétion. Si on éliminait les peines minimales obligatoires, les juges pourraient continuer à faire comme à l'heure actuelle et on aurait l'assurance que l'application de la loi serait la même pour tous.

**Le sénateur Beaudoin:** Nous devrions réfléchir à tout cela.

**M. Scher:** Je voudrais réagir à un de vos autres points, à savoir qu'un meurtre, c'est un meurtre. Je crois que nous serions tous d'accord pour dire, en principe, que le cancéreux qui est en phase terminale et qui va mourir dans les minutes, les heures et les jours qui suivent est très différent du jeune de 12 ans qui est atteint de paralysie cérébrale et dont l'espérance de vie peut aller d'un jour à 70 ou 80 ans et qui est bien vivant et à même d'exercer son rôle d'être humain. Encore là, il y a cette question des circonstances.

I hear you saying that, when you say some murders are different from other murders. You mentioned it when you talked about the Mafia. You are saying that the nature of the murderer may be different. I understand that, and I can accept that. However, I am concerned that we do not differentiate murderers based on the circumstances of the victims, either intentionally or unintentionally.

In my mind, to create a third category of murder, a third-degree murder, would be to do precisely that. It would create a murder charge that, in effect, says, "Here's what will happen. Here is the provision that is in place for people who murder disadvantaged or vulnerable people, because presumably it is motivated by compassion." You may have to define what you mean by "compassion" or "mercy" so as to assist in that adjudication, but it amounts to the same thing. In essence, it also amounts to a de facto acceptance of euthanasia against these groups.

**Senator Beaudoin:** No, because the killer is punished.

**Mr. Scher:** The killer may be punished or may not be. It depends on what you consider as punishment. For example, if someone goes through with this act and gets time served or no punishment, then, in essence, that person is not punished. People may be punished technically, through the legal system, because there is a sentence — maybe probation, maybe a year on the farm — but they are not punished. I do not accept your premise that when you create this third-degree category of murder and convict people, that they will be punished. The whole point of diminishing the mandatory minimum sentence is to ensure that either they are not punished or they are punished less than other murderers would be in different circumstances. In my view, the factor that is differentiating these cases is the circumstances of the victim.

**Senator Corbin:** I never cease to be astonished or to marvel at the way public opinion is formed, especially coming out of so-called public opinion polls. Perception is everything. Perception based on information or disinformation or bad information leads to some understanding, more or less, and finally a judgment call.

I have been bothered by the way the *Latimer* case has been presented by the media generally. I am sure you read the papers, probably more than I do. This is germane to our exercise here, because we have witnesses who come before us and invoke public opinion polls to sustain their theses or their objectives or recommendations.

Would you share some thoughts with us along those lines?

**Mr. Scher:** Let me start by saying that it is the public reaction in the *Latimer* case that in large measure prompted our tremendous concern as a community about these kinds of actions. The Council of Canadians with Disabilities was an intervenor in the Supreme Court of Canada in the *Rodriguez* case, and we were there saying that persons should not be physically prohibited from

C'est ce que je vous entends dire quand vous dites que certains meurtres sont différents d'autres meurtres. Vous y avez fait allusion quand vous avez parlé de la mafia. Vous dites que les meurtriers ne sont pas tous les mêmes. Je comprends cela, et je peux l'accepter. Je veux toutefois éviter que nous fassions, volontairement ou involontairement, des différenciations entre les meurtriers en fonction des circonstances de leurs victimes.

À mon avis, c'est précisément ce qu'on ferait si on créait une troisième catégorie, celle du meurtre au troisième degré. On créerait ainsi une accusation de meurtre qui véhiculerait le message suivant: «Voici ce qui va se passer. Voici la disposition qui s'applique à ceux qui tuent des personnes défavorisées ou vulnérables, car ces personnes sont vraisemblablement animées par un sentiment de compassion.» Il faudra peut-être définir ce qu'on entend par «compassion» ou «pitié» afin de pouvoir prendre cette décision-là, mais cela revient au même. Cela revient ni plus ni moins à une acceptation dans les faits de l'euthanasie à l'égard de ces groupes-là.

**Le sénateur Beaudoin:** Non, puisque le meurtrier est puni.

**M. Scher:** Il pourrait l'être ou ne pas l'être. Tout dépend de ce que vous entendez par «être puni». Quand une personne qui a commis cet acte est condamnée à une peine qui est l'équivalent du temps qu'elle a déjà passé en détention ou qu'elle n'est condamnée à aucune peine, elle n'est finalement pas punie. On peut dire qu'elle est punie en théorie par le système judiciaire puisqu'on lui impose une peine — peut-être la liberté surveillée, peut-être l'interdiction de quitter sa ferme pendant un an —, mais elle n'est pas vraiment punie. Je n'accepte pas votre prémisse selon laquelle ceux qui seront condamnés pour ce nouveau type de meurtre, le meurtre au troisième degré, seront punis. En voulant réduire la peine minimale obligatoire, on cherche essentiellement à éviter que ces gens-là soient punis ou à veiller à ce qu'ils soient punis moins sévèrement que ne le seraient d'autres meurtriers ayant commis un meurtre dans d'autres circonstances. À mon avis, la différenciation ici tient aux circonstances de la victime.

**Le sénateur Corbin:** Je ne cesse jamais d'être étonné par la façon dont l'opinion publique se forme, surtout celle qui s'exprime dans les soi-disant sondages d'opinion. Tout est affaire de perception. La perception qui se fonde sur l'information, la désinformation ou la mauvaise information mène à une certaine compréhension, plus ou moins grande selon le cas, puis à un jugement.

Je suis préoccupé par la façon dont l'affaire *Latimer* a été présentée par les médias, de manière générale. Je suis sûr que vous lisez les journaux, sans doute plus que moi. C'est une idée qui a sa pertinence ici puisque certains des témoins que nous avons entendus ont invoqué les sondages d'opinion à l'appui de leurs thèses ou de leurs objectifs ou de leurs recommandations.

Des commentaires?

**M. Scher:** Je vous dirai tout d'abord que c'est la réaction du public à l'affaire *Latimer* qui, dans une large mesure, est à l'origine de l'énorme inquiétude de notre communauté à l'égard d'actes comme celui-là. Le Conseil des Canadiens avec déficiences était partie intervenante devant la Cour suprême du Canada dans l'affaire *Rodriguez*, où nous avons soutenu qu'une



doing what they would otherwise be able to do if they did not have a disability. We also said, "Don't strike down the law unless and until adequate safeguards are put in place that will protect people with disabilities and others from serious abuse." Then we had Robert Latimer coming along, taking his daughter, placing her in the cab of his truck, killing her, gassing her to death, watching her, timing the amount of time it takes for her to die, planning for it for 10 days, figuring out which way he would do it, and lying to the police about it. I will not go into some of other checkered issues about his past, but there are many facts that are not presented, and the media have a responsibility. Let us be honest here. Two juries of his peers have heard the evidence, have heard the medical evidence about pain, about surgery and about what was required, but despite that evidence have returned verdicts of guilty on murder. However, yes, the public opinion is that this person is a noble and heroic figure, and that concerns me.

**Senator Corbin:** You alluded to other cases.

**Mr. Scher:** Yes.

**Senator Corbin:** The effect of this so-called compassion surrounding the *Latimer* case was an incentive for other people to act.

**Mr. Scher:** We have received calls at our office about that.

**Senator Corbin:** Would the press be responsible for that?

**Mr. Scher:** I think they are in some part.

**Senator Corbin:** I refer to the media generally.

**Mr. Scher:** Frankly, I have some concerns even with respect to this committee's deliberations, because I understand that a report is scheduled to be produced by June 5. If that is the case, it will precede the *Latimer* hearing before the Supreme Court of Canada, which is scheduled to take place on June 14. If you are thinking about a third-degree murder charge or some kind of lessening in sentencing and if your report is released one week before that hearing by the Supreme Court of Canada, I am concerned about what effect that might have. I have every confidence that the justices will not be unduly influenced by your deliberations and your report, because they are experienced and have the independence of their positions, but I am positively sure that the public will be extremely impacted by what you say or do not say.

My request to you on behalf of the Council of Canadians with Disabilities, as an intervenor before the Supreme Court of Canada in the *Latimer* case, is to ask that you delay the release of your report until after the hearing by the Supreme Court of Canada in this matter for precisely the reasons that you have mentioned — the effect of the media on public attitudes, on public thinking, and on the potential impact on our community.

**The Chairman:** I think to some degree you misunderstand the purpose of this committee. We are not here to make any new pronouncements. We are here to review any action that has been

personne ne devrait pas être empêchée physiquement de faire ce qu'elle pourrait faire si ce n'était de sa déficience. Nous avons aussi dit: «N'annulez pas la loi tant et aussi longtemps que des garanties n'auront pas été mises en place pour protéger les personnes ayant des déficiences et d'autres contre des abus flagrants.» Arrive sur ces entrefaites Robert Latimer qui prend sa fille, l'installe sur le siège de sa camionnette, la tue par asphyxie, attend de la voir mourir, mesurant le temps qu'il lui faut pour mourir, après avoir planifié son acte pendant 10 jours et avoir décidé de la méthode qu'il utiliserait et mentant ensuite à la police. Je n'entrerais pas dans les détails moins reluisants de son passé, mais il y a bien des faits qui n'ont pas été présentés, et les médias ont une part de responsabilité. Soyons honnêtes. Deux jurys composés de ses pairs ont entendu les éléments de preuve, ont entendu les preuves médicales concernant la douleur, la chirurgie et ce que nécessitait l'état de sa fille, mais ont néanmoins rendu un verdict de culpabilité pour meurtre. Cependant, vous avez raison, l'opinion publique considère que cet homme est un personnage noble et héroïque, et cela m'inquiète.

**Le sénateur Corbin:** Vous avez fait allusion à d'autres cas.

**M. Scher:** En effet.

**Le sénateur Corbin:** La soi-disant compassion entourant l'affaire *Latimer* a poussé d'autres gens à agir.

**M. Scher:** Nous avons reçu des appels à ce sujet.

**Le sénateur Corbin:** La presse serait-elle responsable de cet état de fait?

**M. Scher:** Je crois qu'elle l'est, en partie.

**Le sénateur Corbin:** Je parle, ici, des médias en général.

**M. Scher:** Franchement, je m'inquiète même de l'effet des travaux du présent comité, parce que je crois savoir que le rapport doit être rendu public le 5 juin. Si c'est bien le cas, ce rapport va précéder la présentation de l'affaire *Latimer* devant la Cour suprême du Canada, le 14 juin. Si l'on songe à porter des accusations de meurtre au troisième degré, ou à réduire la gravité de la sentence, et si votre rapport paraît une semaine avant que la cour suprême n'entende cette cause, je me demande quel effet le rapport va avoir. J'ai tout à fait confiance que les juges ne se laisseront pas influencer indûment par les travaux du comité ni par son rapport, parce qu'il s'agit de gens d'expérience, qui bénéficient de toute l'indépendance voulue. Cependant, je suis tout à fait sûr que ce que vous direz ou ce que vous choisirez de ne pas dire aura une forte incidence sur le public.

Par conséquent, au nom du Conseil des Canadiens avec déficiences, et en tant qu'intervenant devant la Cour suprême du Canada dans l'affaire *Latimer*, je vous prie instamment de retarder la publication de votre rapport, jusqu'après la tenue de l'audience devant la Cour suprême, précisément pour les raisons que vous avez mentionnées, soit l'effet des médias sur l'attitude du public, sur l'opinion publique, et son incidence potentielle sur la collectivité.

**La présidente:** Je crois que, dans une certaine mesure, vous vous méprenez sur le but que poursuit le comité. Nous ne sommes pas ici pour prendre position. Notre mandat consiste à étudier les



taken on initiatives about which we were unanimous. So I do not think your concern is quite valid.

The date was chosen because it is the fifth anniversary of the original release of the document. However, as I have said, we are only dealing with the unanimous recommendations. We will not make new recommendations, but will simply remark upon what the government has done with respect to this or that.

**Mr. Scher:** I understand that, and I am not suggesting that this committee is attempting to influence that process. Further to what Senator Corbin said, whatever you do produce will be heard by the public and will be talked about. That is why you are producing it. Inevitably, that will impact on public views and opinions and, inevitably, in our experience, things will get mixed in together. Although the intent may be simply to do a report card on what governments have or have not done, I do not believe that it will be applied in the media in the way you are suggesting. It will be used to fuel the arguments of one side or the other in whatever agenda or position they are trying to put forward.

With no disrespect to this committee or to you, Senator Carstairs, I am positive that whatever you do produce will be used in that forum, and I request that you postpone the release of your report. I understand that you have time issues, but I am concerned that what you say could have an impact on public discussion and debate about this case.

Part of our concern is that it has been almost impossible to fully undertake a rational debate on some of these issues because of the tremendous emotion evoked based on the responses and the actions that have resulted from public opinion around Sue Rodriguez, Robert Latimer, and this committee's first report, and that further fuel those who may have other agendas.

The practical difficulty I face is that our office has received calls from parents saying that, if Robert Latimer is set free, they will kill their children. As a lawyer, an officer of the court, and a member of the public, that is my grave concern. Whatever the Supreme Court does, whatever you do as a committee, and whatever I do as a representative of the Council of Canadians with Disabilities is all part of that discussion.

My request is simply that you seriously consider delaying the release of your report so that it is not misconstrued, so that its observations, if not recommendations, are not cast into a discussion into which you do not want them cast, because it will not be helpful to the debate that you want to occur.

**Senator Roche:** I understand that on September 30, 1994, the Council of Canadians with Disabilities testified before the committee studying euthanasia and assisted suicide. I was not a

mesures qui ont été prises à propos des initiatives sur lesquelles nous étions unanimes. Je ne crois pas que votre préoccupation soit véritablement valable.

On a choisi la date en question parce qu'il s'agit du cinquième anniversaire de la publication originale du document. Cependant, comme je l'ai dit, nous ne traitons que des recommandations unanimes. Nous n'allons pas faire de nouvelles recommandations; nous allons simplement donner notre opinion sur ce que le gouvernement a fait relativement à telle ou telle mesure.

**M. Scher:** Je le comprends bien, et je ne désire pas laisser entendre que le comité va tenter d'influencer le processus qui va se dérouler. Mais pour reprendre ce qu'a dit le sénateur Corbin, les résultats de vos travaux parviendront au public, qui en discutera. C'est la raison pour laquelle vous étudiez ces questions, justement. Inévitablement, vos travaux auront une incidence sur l'opinion publique. Tout aussi inévitablement, selon notre expérience, on va confondre les choses. Votre intention n'est peut-être que d'accorder une note à ce que les gouvernements ont fait ou n'ont pas fait, mais je ne crois pas que les médias vont présenter la chose ainsi. Ils l'utiliseront pour apporter de l'eau au moulin d'un côté ou de l'autre, selon leurs intentions ou la position qu'ils essaient de vendre.

Avec tout le respect que je vous dois, et que je dois au comité, madame le sénateur, je suis absolument certain que les fruits de vos travaux seront utilisés lors de ce débat, et je vous prie instamment de reporter la publication de votre rapport. Je comprends bien qu'il y a une question d'échéance en jeu, mais je suis fortement préoccupé par le fait que ce que vous direz aura une incidence sur la discussion publique et le débat entourant cette affaire.

Nos inquiétudes sont fondées en partie sur le fait qu'il a été presque impossible d'entreprendre un débat rationnel sur quelques-unes de ces questions en raison des réactions émotives qu'elles ont suscitées, qu'on songe aux réactions qu'on a constatées et aux gestes qui ont été posés autour du cas de Sue Rodriguez, de Robert Latimer, et du premier rapport du présent comité. Dans chacun de ces cas, on a fourni des arguments à des gens qui pourraient avoir des intentions cachées.

Le problème, voyez-vous, c'est que notre bureau a reçu des appels de parents disant que, si Robert Latimer était libéré, ils tueraient leurs enfants. En tant qu'avocat, en tant qu'officier de justice et membre du public, je suis profondément inquiet. Ce que la Cour suprême décidera, ce que le comité va faire, et ce que moi-même je ferai en tant que représentant du Conseil des Canadiens avec déficiences, tout cela fait partie de cette discussion.

Je vous demande tout simplement d'envisager sérieusement de reporter la publication de votre rapport pour qu'il ne soit pas mal compris et pour que les observations, sinon les recommandations qui y sont formulées ne fassent pas l'objet d'une discussion qu'il n'est pas souhaitable d'entamer, car cela ne sera pas utile pour le débat que vous cherchez à avoir.

**Le sénateur Roche:** Le 30 septembre 1994, si je ne m'abuse, le Conseil des Canadiens avec déficiences a témoigné devant le comité saisi de l'étude sur l'euthanasie et l'aide au suicide. Je ne

member of that committee, but I will go back and read your evidence given at that time.

When you testified at that time, did you speak to the committee about your opposition to a third category of murder?

**Mr. Scher:** I honestly do not recall. I do not think we would have, because the concept did not emerge until after that time.

**The Chairman:** My understanding from reading your testimony is that you did not.

**Mr. Scher:** I remember when Bernard Dickens, among others, was introducing this concept. I certainly spoke to him about it at great length.

**Senator Roche:** Thus, when the committee reported with a unanimous recommendation that a third category of murder be created, did you react? Did you send to the government of the day your view on this unanimous recommendation at that time?

**Mr. Scher:** I believe we did, although I cannot say for certain. We certainly made public representations opposing it.

**Senator Roche:** Would you undertake to look into your own records and, if you did communicate with the government concerning this unanimous recommendation made in 1995, will you inform our clerk so that that correspondence can be made available to us?

**Mr. Scher:** I will do that. I can state with certainty that we have publicly spoken out against that recommendation. I have personally debated with Bernard Dickens on *The National* on the CBC, and in various other media, speaking against this recommendation since the time it was made. I know we have written letters. I will provide to the committee whatever we have.

**Senator Roche:** Thank you. I understand that you reject the argument that the appeal of a third category of murder is to enlarge convictions, because prosecutors do not want to press for convictions carrying a mandatory life sentence in cases of "compassionate" murder. I understand that you are rejecting that argument in your rejection of a third category of murder.

I noted that you said that a third category equals euthanasia. Would you enlarge on that for me? The murder has taken place and the argument is that, if there could be a third category with a lesser sentence, the possibilities of conviction would increase because of the possibility of a lesser sentence. As I understand you, you reject that argument because of the integrity of life, because a murder is a murder.

**Mr. Scher:** That may be part of the argument. I agree with that. More fully, with respect to a third category of murder being de facto euthanasia, I was referring to cases in which a conviction was rendered but the penalty was probation or time served, so that

siège pas à ce comité, mais je vais lire le compte rendu de cette audience et lire votre témoignage.

Quand vous avez témoigné alors, avez-vous dit au comité que vous vous opposiez à une troisième catégorie de meurtre?

**M. Scher:** Honnêtement, je ne m'en souviens pas. Cela dit, je ne crois pas, puisque ce concept n'a vu le jour que plus tard.

**La présidente:** Après avoir lu votre témoignage, je dois dire que vous ne l'avez pas fait.

**M. Scher:** Je me souviens du moment où Bernard Dickens, entre autres, a présenté ce concept pour la première fois. Je me suis longuement entretenu avec lui à ce sujet.

**Le sénateur Roche:** Quand le comité a recommandé à l'unanimité dans son rapport la création d'une troisième catégorie de meurtre, avez-vous réagi? Avez-vous signifié au gouvernement de l'époque votre point de vue sur cette recommandation unanime?

**M. Scher:** Je crois que nous l'avons fait, quoique je n'en sois pas certain. De toute façon, nous nous y sommes opposés à plusieurs reprises en public.

**Le sénateur Roche:** Vous pourriez peut-être faire une petite recherche dans vos propres dossiers, et si vous découvrez que vous avez effectivement communiqué avec le gouvernement concernant cette recommandation unanime faite en 1995, pourriez-vous en informer notre greffier de sorte qu'il puisse nous communiquer l'information?

**M. Scher:** Absolument. Je peux vous dire avec certitude que nous nous sommes prononcés publiquement contre cette recommandation. J'ai débattu de la question personnellement avec Bernard Dickens à l'émission *The National* sur le réseau anglais de la SRC, et dans d'autres médias également, et je me suis toujours opposé à cette recommandation, depuis sa formulation initiale. Je sais que nous avons également envoyé des lettres. Je fournirai au comité tout ce dont nous disposons.

**Le sénateur Roche:** Je vous remercie. Je crois comprendre que vous rejetez l'argument voulant que l'attrait d'une troisième catégorie de meurtre tient au fait que les procureurs auront à choisir parmi un éventail élargi de condamnations, dans la mesure où ils n'auront plus à chercher à obtenir des condamnations assorties d'une peine obligatoire d'emprisonnement à vie dans les cas de meurtre «par compassion». Vous rejetez cette hypothèse, si je ne m'abuse, en rejetant la troisième catégorie de meurtre.

J'ai remarqué que vous avez dit qu'une troisième catégorie serait l'équivalent de l'euthanasie. Pourriez-vous me donner une explication? Le meurtre a déjà été commis. L'hypothèse avancée est la suivante: si on pouvait avoir une troisième catégorie de meurtre assortie d'une peine inférieure, les possibilités d'obtenir une condamnation seraient meilleures étant donné la possibilité d'imposer une peine inférieure. Si j'ai bien compris votre propos, vous rejetez cet argument par respect pour l'intégrité de la vie: un meurtre est un meurtre.

**M. Scher:** Cela est peut-être vrai en partie, je le concède. Cela étant, quant à la troisième catégorie de meurtre qui serait une euthanasie de fait, je parlais en réalité de cas où l'on a obtenu une condamnation, mais où la peine était la probation ou le temps



there really was no penalty for the murder. The murder was acknowledged on the books, but no action was taken in terms of addressing it, in the sense that there was no penalty for it other than time served or probation.

**Senator Roche:** To implement your preferred solution to this problem would require an amendment to the Criminal Code.

**Mr. Scher:** No, my preferred solution is to leave things as they are, as I stated from the beginning. I said that, if you are intent on changing the Criminal Code, a less dangerous mechanism by which to do that, from my community's perspective, would be to consider removing mandatory minimum sentences across the board, if you create a third category of murder targeting my community and others as the victims.

**Senator Roche:** To implement your suggestion of rejecting a third category would require changing what was a unanimous recommendation. I want to be sure that you are in fact recommending that we change what was a unanimous recommendation in 1995.

**Mr. Scher:** That is and is not true. As I understood the recommendation, you wanted to ensure that there was some discretion with respect to sentencing in these matters. You can do that in the way I have described. If you took away mandatory minimum sentences you would have that discretion. You do not need a third category of murder to do that. On the contrary, by creating a third category of murder you are, I believe, creating a two-tier system of justice. Those who kill people who are not disabled or vulnerable will be subject to a mandatory minimum sentence of life in prison without parole for a specified period of time, and those who murder people who are disabled will be subject to a sentence that is within the discretion of the trial judge. Therefore, it creates a two-tier system of justice.

My suggestion is not to do that, but to maintain the existing system, and perhaps to look at other ways in which prosecutors, in their charging and sentencing practices, can address some of your concerns that led you to make this recommendation. More specifically, you can address it very simply by removing mandatory minimum sentences, if that is what you choose to do. That addresses your concern and the recommendation the committee made.

**Senator Roche:** I will think further about this.

**The Chairman:** Yes, we will all do that.

Thank you very much, Mr. Scher, for your presentation. It was extremely thought-provoking and very useful to our deliberations.

Our next panel is from Campaign Life.

Honourable senators, all of these witnesses have been told that we are not doing an opening of the non-unanimous recommendations on euthanasia and assisted suicide. They will be limiting their presentation today to the aspects of the report that had unanimous recommendations.

passé en détention préventive, ce qui revient à dire qu'il n'y a pas eu de punition pour le meurtre. Le meurtre a été consigné par écrit dans les livres, mais aucune mesure n'a été prise pour corriger le tort, dans la mesure où la seule peine qui a été imposée a été la probation ou la durée de la détention préventive.

**Le sénateur Roche:** L'adoption de la solution que vous privilégiez exigerait de modifier le Code criminel.

**M. Scher:** Non, la solution que je préconise est de laisser les choses telles qu'elles sont, comme je l'ai dit au début de mon intervention. J'ai dit que si on a vraiment l'intention de changer le Code criminel, l'une des façons les moins dangereuses de le faire, du point de vue du groupe que je représente, serait d'envisager d'éliminer les peines minimums obligatoires dans tous les cas, notamment si on crée une troisième catégorie de meurtre visant le groupe que je représente et d'autres victimes.

**Le sénateur Roche:** Pour rejeter, comme vous le suggérez, la troisième catégorie, il faudrait changer ce qui était une recommandation unanime. Je veux être sûr de bien vous comprendre: vous nous recommandez de revenir sur une recommandation qui avait fait l'unanimité en 1995, n'est-ce pas?

**M. Scher:** Oui et non. Si j'ai bien compris la recommandation, vous vouliez que dans ces cas-là la détermination de la peine soit faite de façon discrétionnaire. Or, il est possible d'y parvenir si on suit la méthode que j'ai décrite. En fait, il est possible d'avoir la latitude voulue si on supprime les peines minimales obligatoires. Nul besoin de créer une troisième catégorie de meurtre. Car, au contraire, si vous créez effectivement une troisième catégorie de meurtre, vous mettez en place, à mon avis, un système de justice à deux vitesses. Ceux qui tueront des gens qui ne sont ni vulnérables ni handicapés pourront être condamnés à une peine minimale obligatoire et emprisonnés à vie sans avoir droit à la libération conditionnelle pendant un temps bien déterminé, alors que ceux qui tueront des gens handicapés seront condamnés à une peine qui sera laissée à la discrétion du juge de première instance. C'est ce que j'appelle créer un système de justice à deux vitesses.

Je ne vous suggère pas de le faire, mais plutôt de maintenir le régime actuel, tout en vous demandant par quel autre moyen les procureurs pourront tenir compte, dans leur pratique de mise en accusation et de détermination de la peine, de certaines des préoccupations qui ont donné lieu à votre recommandation. Vous pouvez régler tout cela de façon très simple et de façon plus spécifique en supprimant la peine minimale obligatoire, si c'est ce que vous décidez de faire, ce qui pourrait répondre à vos préoccupations et correspondre à la recommandation du comité.

**Le sénateur Roche:** Il faudra que j'y pense plus longuement.

**La présidente:** C'est ce que nous devons tous faire.

Monsieur Scher, merci beaucoup de votre exposé très inspirant, qui nous servira beaucoup dans notre réflexion.

Nous accueillons maintenant la Coalition Campagne vie.

Honorables sénateurs, sachez que l'on a averti tous les témoins que nos audiences ne serviraient pas à rouvrir les recommandations sur l'euthanasie et l'aide au suicide qui n'ont pas fait l'unanimité. Par conséquent, les témoins confineront donc tous leurs propos aux aspects du rapport qui ont fait l'unanimité.



We will begin with Mr. Peter Ryan.

**Mr. Peter Ryan, President, Campaign Life Coalition New Brunswick:** Honourable senators, thank you for this opportunity to appear before you today. I hope you all have copies of my statement.

Campaign Life Coalition believes in the equal right to life for all human beings. We believe the right to life is a fundamental principle of justice that must be protected in our laws and culture. We are concerned about the weak and vulnerable members of our society, those who are dependent upon others, those who consequently have little or no voice in whether they live or die, be they a preborn child, a young infant with disabilities, a person in a so-called vegetative state due to an accident, an older person with Alzheimer's, or someone debilitated by terminal illness.

I have had a great interest in euthanasia and end of life issues for a number of years. In 1994, when I was working for the Catholic Archdiocese of Vancouver, I assisted Archbishop Adam Exner in his submission to the Special Senate Committee on Euthanasia and Assisted Suicide. In 1996, I completed a dissertation in theological ethics for the Pontifical Lateran University of Rome. My dissertation topic was the Canadian debate over legalized euthanasia. I examined the debate between 1992 and 1995. A large part of the study dealt with the Senate committee hearings and the report "Of Life and Death." I am therefore quite interested to see how you will update the report.

Campaign Life Coalition is concerned about the recommendation on compassionate homicide. I believe that some other members of the panel will cover that topic quite well. My main reason for being here today is to speak to you about the withholding and withdrawal of life-sustaining treatment and the possible connection, in some cases, with non-voluntary euthanasia. As you know, the potential link between these two topics, the omission of treatment and euthanasia, is not something that "Of Life and Death" expressly covers. We are therefore talking about new territory that you could cover as you update the report.

As you review the whole area of withholding and withdrawing treatment and your unanimous recommendations in that regard, as covered in chapter 5 of the report, we ask you to give some consideration to the problem of undertreatment as well as the problem of overtreatment. By "undertreatment", I especially mean when a non-competent patient is denied beneficial, non-burdensome treatment because of someone's prejudice with respect to the patient's disability, age or illness. During the hearings of the Senate Committee on Euthanasia, a number of witnesses reported existing problems of undertreatment, particularly in regard to disabled persons.

The report calls for legal reform in regard to the withholding and withdrawal of treatment. It seems that the type of reform envisioned would make it easier for doctors and others to omit

Nous commençons par M. Peter Ryan.

**M. Peter Ryan, président, Coalition Campagne vie du Nouveau-Brunswick:** Mesdames et messieurs, merci de m'accueillir aujourd'hui. J'espère que vous avez tous reçu un exemplaire de ma déclaration.

La Coalition Campagne vie croit que les êtres humains ont tous le même droit à la vie. Le droit à la vie est un principe fondamental de justice qui doit être protégé dans nos lois et dans notre culture. Nous avons à coeur le sort des faibles et des vulnérables de notre société, qui dépendent des autres et qui ont donc peu ou prou voix au chapitre quand il s'agit de décider s'ils doivent vivre ou mourir, que l'on parle d'un enfant à naître, d'un nourrisson handicapé, d'une personne dans un état végétatif à la suite d'un accident, d'une personne âgée souffrant de la maladie d'Alzheimer ou de quelqu'un dont la maladie terminale a un effet débilant.

Je m'intéresse de très près et depuis plusieurs années à la question de l'euthanasie et de la fin de la vie. En effet, en 1994, alors que je travaillais à l'archidiocèse catholique de Vancouver, j'ai aidé l'archevêque Adam Exner à préparer son témoignage au Comité sénatorial spécial sur l'euthanasie et l'aide au suicide. En 1996, j'ai terminé un mémoire sur la déontologie théologique à l'Université pontificale du Latran à Rome. Le sujet de mon mémoire? Le débat canadien entourant la légalisation de l'euthanasie. J'ai étudié ce qui s'était dit là-dessus de 1992 à 1995. Une bonne partie de mon étude portait sur les audiences du comité sénatorial et sur son rapport «De la vie et de la mort». Vous comprenez pourquoi je suis curieux de savoir comment vous allez mettre à jour votre rapport.

La Coalition Campagne vie s'inquiète de la recommandation portant sur le suicide par compassion. Je crois que d'autres membres de la table ronde s'intéresseront eux aussi à cette question. Si je suis ici aujourd'hui, c'est principalement pour vous parler du refus d'administrer un traitement de survie ou de l'interruption de son administration ainsi que du lien que l'on peut parfois faire dans certains cas entre cela et l'euthanasie non volontaire. Vous savez que le lien possible entre, d'une part, refuser d'administrer un traitement et, d'autre part, l'euthanasie est une question dont ne traite pas de façon expresse le rapport «De la vie et de la mort». Il s'agit donc d'une question inédite dont vous voudrez peut-être traiter dans votre mise à jour.

Quand vous examinerez toute la question de la suppression du traitement et vos recommandations unanimes à cet égard, au chapitre 5 du rapport, nous vous invitons à vous pencher sur le problème du sous-traitement aussi bien que celui du sur-traitement. Par «sous-traitement», je veux parler du cas où l'on refuse à un patient privé de ses facultés le bénéfice d'un traitement utile et non excessif en raison des préjugés de quelqu'un à propos du handicap, de l'âge ou de la maladie du patient. Durant les audiences du Comité sénatorial sur l'euthanasie, divers témoins ont souligné les problèmes de sous-traitement, notamment dans le cas des personnes handicapées.

Le rapport prévoit une réforme juridique des dispositions d'omission ou d'interruption du traitement. La réforme envisagée permettrait aux médecins et à d'autres personnes d'omettre plus

treatment. That might be a good thing in many ways. However, would there not be a real danger that making the withholding and withdrawal of treatment easier could also make undertreatment more of a problem? In any case, I believe the area of undertreatment deserves the committee's close attention, for it affects the basic rights of all citizens to life and health care.

As one considers the phenomenon of undertreatment, there is a basic ethical and legal question that I believe to be pertinent. Can the withholding or withdrawal of life-sustaining treatment sometimes be homicidal? Can it sometimes also be an instance of euthanasia? Please note the word "sometimes". The "sometimes" I am asking you to consider are cases when patients die after being denied beneficial, non-burdensome life-sustaining treatment without their consent. Is it fair to consider such cases as homicide or euthanasia?

Just to clarify the question, I am not asking you whether any case where a patient dies after treatment is withheld or withdrawn is an act of homicide or euthanasia. That is actually a non-issue. People die every day in our country after unnecessary medical treatment has been omitted by doctors. Are those doctors killers? Of course not. We are not talking about situations where people refuse treatment that they consider to be either not beneficial or else burdensome for them. Nor are we talking about cases where parents or other proxies decide to withhold or withdraw unnecessary treatment for a non-competent patient for whom they are responsible. The focus here is on beneficial, non-burdensome treatment.

Now when we consider this question, "Can the withholding or withdrawal of life-sustaining treatment sometimes be homicidal?", we should realize that the law is not silent. Most legal scholars agree that the Criminal Code's answer to the question is yes. The answer permeates essentially sections 215 to 217 of the code. What scope of cases is caught by these provisions may be a matter for debate, but the basic principle — that the omission of treatment can be homicidal — seems clear.

I found it curious that "Of Life and Death" neither addresses nor specifically answers the question of whether the withholding or withdrawing of treatment can be homicidal. However, reading between the lines, one gets the impression that the report is inclined towards a negative position on the question. I wonder how the members of this committee read it. In any case, I suggest it would be helpful for the committee to clarify its own position on the matter. If the Criminal Code says that treatment omissions can be homicidal, and the committee is considering the need for law reform with respect to the withholding and withdrawing of treatment, it would seem that this issue of whether omissions can be homicidal must be addressed before meaningful reform can occur.

It might be that the committee would want to clarify that its position is that the withholding and withdrawal of treatment is not homicidal. The reason it might wish to offer that opinion might be

facilement un traitement. Cela pourrait être une bonne chose à maints égards. Toutefois, le fait de faciliter cette omission ou cette interruption ne risquerait-il pas de poser de façon plus aiguë le problème du sous-traitement? Quoi qu'il en soit, je crois qu'il faut que le comité se penche de près sur le problème du sous-traitement, car c'est quelque chose qui touche aux droits fondamentaux de tous les citoyens à la vie et à des soins de santé.

Le phénomène du sous-traitement soulève une question morale et juridique tout à fait pertinente à mon avis. L'omission ou l'interruption d'un traitement qui maintient un patient en vie peut-elle dans certains cas constituer un homicide? Peut-il s'agir parfois d'euthanasie? Vous remarquerez que j'emploie le terme «parfois». Ce que je veux dire, c'est que je vous invite à vous pencher sur le cas de patients qui meurent après qu'on leur a retiré la possibilité d'être maintenus en vie à l'aide de traitements utiles et non excessifs sans leur consentement. Peut-on considérer dans ce cas qu'il y a eu homicide ou euthanasie?

Pour clarifier les choses, je ne vous demande pas de décréter que tous les cas où un patient décède après l'interruption ou l'omission d'un traitement constituent un homicide ou une forme d'euthanasie. Cette question ne se pose pas. Il y a des gens qui meurent tous les jours au Canada parce que des médecins ne leur ont pas administré des traitements qui n'étaient pas indispensables. Est-ce que ces médecins sont des meurtriers? Bien sûr que non. Nous ne parlons pas non plus des cas où des individus refusent des traitements qu'ils jugent inutiles ou trop lourds pour eux. Nous ne parlons pas non plus des cas où des parents ou d'autres personnes habilités décident d'interrompre ou d'omettre des traitements qui ne sont pas indispensables pour le patient dont ils sont responsables. Nous parlons ici de traitements utiles et non excessifs.

À propos de la question de savoir si l'omission ou la suppression d'un traitement de maintien en vie peut parfois constituer un homicide, il faut bien savoir que la loi n'est pas muette à ce sujet. La plupart des experts juridiques reconnaissent que la réponse du Code criminel à cette question est oui. Elle est présente en substance dans les articles 215 à 217 du code. On peut discuter de la portée exacte de ces dispositions, mais le principe fondamental, l'idée que l'omission de traitement peut constituer un homicide, semble clair.

J'ai trouvé étrange que le rapport «De la vie et de la mort» n'ait ni posé ni résolu la question de savoir si la suppression ou l'omission d'un traitement avait un caractère d'homicide. Toutefois, en lisant entre les lignes, on a l'impression que le rapport tendrait à répondre par la négative à cette question. Je me demande comment les membres de ce comité l'interprètent. Quoi qu'il en soit, je pense qu'il serait bon que le comité précise sa position sur la question. Si, d'après le Code criminel, ces omissions peuvent constituer un homicide, et si le comité estime qu'il faut réformer les dispositions juridiques concernant la suppression ou l'omission de traitement, je pense qu'il faudrait sérieusement étudier la question avant de pouvoir mettre en place une réforme sérieuse.

Peut-être le comité voudra-t-il dire clairement qu'à son avis la suppression ou l'omission d'un traitement ne constitue pas un homicide. Il pourrait le dire en se fondant sur l'idée que lorsqu'un



that when death occurs following the omission of treatment, it is only nature taking its course. Thus, there is no intent to cause death as there is with homicide. That would be a simple and straightforward position to adopt, but does it hold up to scrutiny? I suggest that it does not.

If you or I were to walk into a hospital and start pulling out plugs on patients' equipment, if we were to start disconnecting respirators, IV lines and feeding tubes, if we were to remove the medicines and technologies that are keeping people alive, would we get away with it? If some patients died as a result of our actions, could we be charged with causing death under the current law? There is not much doubt that we could be charged, and most Canadians would have no problem with that law as it now stands. The question is whether the committee favours a change in the law. If you take the position that the withholding and withdrawal of treatment cannot be homicidal, you logically must be in favour of changing the law to make it impossible to charge homicide against anyone who denies another person medical treatment.

Part of the difficulty in discussing the whole area of undertreatment and denial of treatment is the lack of relevant and familiar cases. In the literature on the subject, there is one common case regarding a Down's syndrome child with a life-threatening bowel obstruction. What happens if the parents refuse the necessary surgery and the child dies? We would have an instance of medical treatment that is fairly routine and beneficial to the patient, not really a burdensome treatment, yet it was denied. Why? Evidently because the parents thought it would be better for their disabled child to die and be spared a life of suffering. The question is this: Were these parents responsible for the death of their child, or were they simply letting nature take its course? I would say *prima facie* that they were responsible; however, their motive was merciful, which would qualify such a death, in my opinion, as non-voluntary euthanasia and not simply homicide.

When Professor Downie of Dalhousie University appeared before this committee, she referred to the Skeena B. case wherein the court affirmed that, if parents refuse treatment that is in their minor child's best interests, the state can override the refusal. However, if you say that in omitting treatment for children parents are simply letting nature take its course, it does not give the state much of a leg to stand on in intervening in such cases, does it?

While we have not had many well-known Canadian cases of people dying after being denied treatment, the British public has had the benefit of numerous cases, especially with regard to nutrition and hydration. In the cases most recently publicized in the press, it seems many elderly people were deprived of nutrition and hydration because of their caregivers' prejudice about their age.

patient décède après qu'un traitement a été omis, son décès n'est que naturel. Il n'y a donc pas d'intention de donner la mort comme c'est le cas quand on parle d'homicide. Ce serait une position simple et claire à adopter, mais résisterait-elle à un examen approfondi? Je ne le crois pas.

Si nous entrions, vous ou moi, dans un hôpital et si nous commençons à débrancher des appareils, à débrancher des respirateurs, des tuyaux de perfusion ou d'alimentation, si nous enlevons les médicaments et les technologies qui maintiennent en vie des patients, croyez-vous que nous pourrions le faire en toute impunité? Si des patients mouraient à cause de cela, pourrions-nous être accusés d'avoir entraîné leur mort en vertu des lois actuelles? Je pense qu'il est clair que nous pourrions être condamnés, et que la plupart des Canadiens seraient tout à fait d'accord avec les dispositions actuelles du droit. La question est de savoir si le comité souhaite modifier ces dispositions. Si vous considérez que l'omission ou l'interruption du traitement ne constitue pas un homicide, vous devez logiquement proposer qu'on modifie la loi de façon à ce qu'il devienne impossible d'accuser d'homicide quelqu'un qui n'aura pas accordé un traitement médical à une autre personne.

Quand on parle du sous-traitement ou du non-traitement, la difficulté vient en partie du fait qu'on n'a pas suffisamment de cas pertinents et familiers. Dans les documents qui traitent de la question, on se réfère souvent au cas d'un enfant trisomique atteint d'une obstruction intestinale qui risquait d'entraîner la mort. Que se passerait-il si les parents refusaient l'opération et que l'enfant mourait? En l'occurrence, il s'agissait d'un traitement médical assez banal et utile pour le patient, d'un traitement qui n'était pas excessif, et pourtant on ne l'a pas fait. Pourquoi? De toute évidence parce que les parents estimaient qu'il valait mieux laissé l'enfant mourir pour lui épargner une vie de souffrance. La question est la suivante: ces parents étaient-ils responsables de la mort de leur enfant, ou ont-ils simplement laissé la nature suivre son cours? Je dirais a priori qu'ils étaient responsables; toutefois, ils ont agi par compassion, de sorte que ce décès à mon avis devrait être considéré comme une forme d'euthanasie non volontaire, et non comme un homicide.

Quand la professeure Downie, de l'université Dalhousie, a comparu devant votre comité, elle a parlé du cas de Skeena B., à propos duquel le tribunal avait affirmé que, si les parents refusaient un traitement qui était dans l'intérêt de leur enfant mineur, l'État pouvait passer outre à ce refus. Toutefois, si vous dites qu'en omettant un traitement les parents laissent simplement la nature suivre son cours, vous ne laissez pas beaucoup de possibilité d'intervention à l'État, n'est-ce pas?

Nous ne connaissons pas beaucoup de cas de Canadiens morts des suites de l'omission de traitement, mais en Grande-Bretagne il y a eu de nombreux cas de ce genre, notamment liés à l'alimentation ou à l'hydratation. Les affaires les plus récentes relatées dans la presse parlent de nombreuses personnes âgées privées d'alimentation et déshydratées par des personnes responsables de leurs soins qui avaient des préjugés à leur égard et les considéraient comme des vieillards.



I believe Alex Schadenberg will speak on those cases later today so I will not dwell on them, but I do note that public concern for this area of undertreatment and denial of treatment has fuelled support for the Medical Treatment (Prevention of Euthanasia) Bill. That bill has now passed second reading and recently was reported back from committee to the house.

The core part of the bill states:

It shall be unlawful for any person responsible for the care of a patient to withdraw or withhold from the patient medical treatment or sustenance if his purpose or one of his purposes in doing so is to hasten or otherwise cause the death of the patient.

I wonder how your committee might feel about having such legislation here. It might help clarify the law in the area of withholding and withdrawing treatment, might it not?

The idea that death can be caused by the omission of treatment and that euthanasia can be a matter of omission as well as an act is not new or esoteric. It is upheld in the Criminal Code, as I mentioned. It was supported by a considerable number of witnesses who appeared before the Senate Committee on Euthanasia, including prominent scholars such as Edward Keyserlingk and Margaret Somerville. It is part of the official teaching of the Catholic Church, which defines euthanasia as an act or omission aimed at relieving suffering.

If one accepts that the omission of treatment can sometimes be homicide, there is still the large and important question of when it is homicide and when it is not. That can be a difficult question to face, but the difficulty of applying some principles should not lead us to disregard the importance of the principles themselves. I suggest that the committee give further consideration to the question of undertreatment and denial of treatment. I should like to see the committee clarify that non-voluntary euthanasia can take place by act or omission. I should like to see the committee's approach to the withholding and withdrawal of treatment address the question of whether the omission of treatment can sometimes be homicidal. In any case, I wish the committee well in your deliberations.

**The Chairman:** Thank you, Mr. Ryan. Now we will hear from Mr. Schadenberg.

**Mr. Alex Schadenberg, Executive Director, Euthanasia Prevention Coalition of Ontario:** Honourable senators, on February 23, 1994, the Special Senate Committee on Euthanasia and Assisted Suicide was appointed to examine and report on the legal, social and ethical issues relating to euthanasia and assisted suicide. That committee heard testimony for 14 months from more than 150 witnesses from all across Canada, while also receiving hundreds of additional letters and briefs. The result of that extensive review of the issues was its final report, "Of Life and Death."

The Euthanasia Prevention Coalition of Ontario recognizes the awesome task that existed in producing that final report. We hope that some of the recommendations will eventually be

Je crois qu'Alex Schadenberg vous en parlera plus tard, et je ne vais donc pas m'étendre sur ces affaires, mais je constate que l'inquiétude du public à l'égard de cette question du sous-traitement ou de l'omission du traitement a alimenté l'appui au projet de loi sur le traitement médical (prévention de l'euthanasie). Ce projet de loi a maintenant reçu la deuxième lecture, et le comité a fait rapport à la Chambre.

Ce projet de loi stipule ceci:

Il est illégal pour une personne responsable du soin d'un patient d'omettre ou d'interrompre un traitement médical ou un dispositif de soutien pour ce patient si le seul but de cet acte est de hâter ou d'entraîner de quelque façon le décès du patient.

Je me demande ce que penserait votre comité de légiférer sur ce point. Cela permettrait peut-être de clarifier les dispositions du droit concernant l'omission ou l'interruption du traitement, n'est-ce pas?

L'idée que la mort peut être entraînée par l'omission d'un traitement et que l'euthanasie peut aussi être entraînée par une omission aussi bien que par un acte n'a rien de nouveau ou d'ésotérique. Comme je l'ai dit, le Code criminel l'appuie. Elle a aussi reçu l'appui de nombreux témoins qui ont comparu au Comité sénatorial sur l'euthanasie, notamment d'éminents érudits tels que Edward Keyserlingk et Margaret Somerville. Cela fait aussi partie de l'enseignement officiel de l'Église catholique, qui définit l'euthanasie comme un acte ou une omission visant à atténuer des souffrances.

Même si on considère que l'absence de traitement peut parfois constituer un homicide, une question importante demeure, celle de savoir quand il y a homicide, et quand ce n'est pas le cas. Cela peut être une question difficile, mais ce n'est pas parce que certains principes sont difficiles à appliquer qu'il faut ignorer l'importance de ces principes. À mon avis, le comité devrait continuer à approfondir l'insuffisance de traitement et l'absence de traitement. J'aimerais que le comité précise qu'un acte d'omission peut constituer une forme d'euthanasie non volontaire. J'aimerais que le comité cherche à déterminer dans quelle circonstances l'absence de traitement peut parfois constituer un homicide. Dans tous les cas, je souhaite que vos délibérations soient couronnées de succès.

**La présidente:** Merci, monsieur Ryan. Nous allons maintenant entendre M. Schadenberg.

**M. Alex Schadenberg, directeur exécutif, Euthanasia Prevention Coalition of Ontario:** Honorables sénateurs, le 23 février 1994, un comité spécial du Sénat était formé pour examiner, afin d'en faire rapport, les questions juridiques, sociales et éthiques liées à l'euthanasie et au suicide assisté. Le comité a siégé 14 mois pendant lesquels il a entendu plus de 150 témoins et reçu des centaines de lettres et de mémoires. À l'issue de ce vaste examen des questions en cause, le comité a publié son rapport, intitulé «De la vie et de la mort».

La Euthanasia Prevention Coalition of Ontario reconnaît combien la mise au point de ce rapport a constitué une tâche formidable. De plus, elle espère que bon nombre des

implemented, but we also find fault with the logic behind some other recommendations.

Three of the recommendations we oppose deal with the issue that we have been asked to address today. These recommendations surround issues regarding compassionate homicide. We define "compassionate homicide" as the deliberate killing of someone by action or omission in order to end that person's suffering. The Special Senate Committee on Euthanasia unanimously recommended that the Criminal Code be amended to provide for a less severe penalty in cases where there is an essential element of compassion or mercy.

The committee recommended that Parliament consider certain options. One option was that a third category of murder could be created that would not carry a mandatory life sentence but rather would carry a less severe penalty. Or a separate offence of compassionate homicide could be established that would carry a less severe penalty. The essential elements of compassion and mercy must be clearly and narrowly defined in order to limit the cases in which a less stringent sentence would be available. The committee did not offer a definition that would be suitably narrow and acceptable to Parliament; there was no definition. Parliament would determine the appropriate penalty.

There was also a majority recommendation that voluntary euthanasia remain a criminal offence but that the Criminal Code be amended to allow for a less severe penalty, similar to that provided for non-voluntary euthanasia in cases where there is an essential element of compassion or mercy. We applaud the part of this recommendation to preserve the Criminal Code offence with respect to voluntary euthanasia. We oppose the less severe penalty where there is the essential element of compassion or mercy. That recommendation is probably not on the table today because it did not receive unanimous support, but I address it today in any event. The "less severe penalty" portion of the recommendation probably had unanimous approval, knowing that the minority recommended that, if voluntary euthanasia remains a criminal offence, the Criminal Code be amended to provide for a less severe penalty similar to the penalty for non-voluntary euthanasia.

There is a third and unanimous recommendation that the Euthanasia Prevention Coalition of Ontario sees as connected to the compassionate homicide issue. That is the recommendation in chapter 5 concerning artificial hydration and nutrition, which the committee agreed constituted treatment. Thus the withholding or withdrawal of artificial hydration and nutrition is acceptable in some circumstances, as is the withholding and withdrawal of artificial respiration, blood transfusions and CPR. We connect that recommendation to compassionate homicide because unethical family members, friends and medical caregivers can use the licence of that recommendation to starve an incompetent person to death, especially when the incompetent person is persistently living against their wishes or the wishes of others or is costing

recommendations qu'il renferme seront mises en oeuvre. Toutefois, certaines recommandations lui paraissent fautive et elle ne peut en percevoir la logique.

Trois des recommandations auxquelles nous nous opposons concernent la question qu'on nous a demandé de commenter aujourd'hui, soit celle de l'«homicide par compassion». Notre coalition définit de la façon suivante l'«homicide par compassion»: meurtre volontaire, par action ou omission, dans le but de mettre fin aux souffrances de la personne concernée. Le comité sénatorial spécial a recommandé à l'unanimité de modifier le Code criminel afin de permettre l'imposition d'une peine moins sévère dans le cas où intervient l'élément essentiel de compassion ou de pitié.

Il recommandait au Parlement d'envisager les options suivantes. Une option était de créer une troisième catégorie de meurtre qui entraînerait une peine moins sévère que la peine obligatoire d'emprisonnement à perpétuité; ou encore, on pourrait créer une infraction distincte d'homicide par compassion qui entraînerait une peine moins sévère. Les éléments essentiels de compassion ou de pitié doivent être clairement et strictement définis afin de limiter les cas admissibles à une peine moins sévère. Le comité n'a pas proposé de définition susceptible d'être assez étroite et que le Parlement pourrait juger acceptable. Il n'y aurait donc pas de définition; c'est le Parlement qui déterminerait la peine appropriée.

Une majorité des membres du comité a également recommandé que l'euthanasie volontaire demeure une infraction criminelle. Mais on devrait modifier le Code criminel afin de permettre l'imposition d'une peine moins sévère, semblable à celle prévue pour les cas d'euthanasie non volontaire où intervient l'élément essentiel de compassion ou de pitié. La partie de cette recommandation prévoyant que l'euthanasie volontaire demeure une infraction criminelle nous réjouit, mais nous nous opposons à l'imposition d'une peine moins sévère pour les cas où intervient l'élément essentiel de compassion ou de pitié. Cette recommandation n'est pas à l'étude aujourd'hui, sans doute parce qu'elle n'était pas unanime, mais je tiens à en parler parce que l'idée de permettre l'imposition d'une peine moins sévère a probablement fait l'unanimité, étant donné que la majorité a recommandé que, si l'euthanasie volontaire demeure une infraction criminelle, on modifie le Code criminel afin de permettre l'imposition d'une peine moins sévère, semblable à celle prévue pour l'euthanasie non volontaire.

Une troisième recommandation que notre coalition associe à l'homicide par compassion figure au chapitre 5. Elle a été adoptée à l'unanimité et concerne l'hydratation et l'alimentation artificielles considérées par le comité comme des formes de traitement. Ainsi, dans certaines circonstances, il est acceptable de ne pas administrer l'hydratation et l'alimentation artificielles ou de les interrompre, comme c'est le cas également de la respiration artificielle, des transfusions sanguines ou de la réanimation cardiorespiratoire. La raison pour laquelle nous associons cette recommandation à l'homicide par compassion, c'est que des personnes dépourvues de sens moral, membres de la famille, amis ou fournisseurs de soins, pourraient s'en prévaloir pour affamer jusqu'à ce que mort s'ensuive une personne frappée d'incapacité,



others too much either by monetary, emotional, psychological or social means. I will comment on that later.

We oppose any changes to the Criminal Code that would allow for a lesser sentence for compassionate homicide. We believe that that concept would essentially lead to a situation where all human beings are not equal under the law and would not be equally protected. We also believe that any compassionate homicide law would be devised to deal with hard cases such as the *Latimer* case. Whereas we recognize that these cases have particular difficulties with respect to conviction, we also recognize that hard cases make bad laws. Adjusting the Criminal Code to deal with these hard cases will open up a series of new problems that will be far worse than the current dilemma.

To illustrate new problems occurring from establishing a compassionate homicide exemption in the Criminal Code, let us consider two optional changes to the Criminal Code. The first option is a broadly defined compassionate homicide exemption in the Criminal Code equally applied to all homicides so long as one claims and has reasonable proof of compassionate motives for one's act. This would involve the creation of a new class of third degree or compassionate homicide, eliminating minimum penalties only for homicide that is motivated by compassion or mercy. There are two serious problems with this approach.

The first problem is that motivation is not observable. We cannot determine the motivation of an act in the same way we are able to determine the facts of an act. This is accentuated by two principles of our Canadian justice: guilt must be proven beyond a reasonable doubt and defendants cannot be required to testify at their own trials. Therefore, any time the defence claimed that their client was motivated by compassion, the prosecution would be forced to prove beyond a reasonable doubt that compassion was not the motive and to do so without having the opportunity to examine the defendant in court. This would result in a disproportionate number of cases claiming to be compassionate homicide. Therefore, family members or friends who kill their wealthy, elderly, disabled or incompetent loved ones could claim a motive of compassion, and it would be very difficult to prove that the real motive was, for example, greed.

The second problem is that compassion can be broadly defined. What is compassion? In what situations would the homicide be considered to be compassionately motivated? On the Internet at [www.dictionary.com](http://www.dictionary.com), we found three definitions of compassion. The first was:

Deep awareness of the suffering of another coupled with the wish to relieve it.

Here pity was listed as a synonym. A second definition was:

en particulier si cette personne s'acharne à vivre contre la volonté des autres ou qu'elle coûte trop cher aux autres, compte tenu de leurs moyens financiers, émotifs, psychologiques ou sociaux. Nous y reviendrons.

Nous nous opposons à toute modification du Code criminel qui permettrait d'imposer une peine moins sévère pour homicide par compassion. À notre avis, cette notion conduirait essentiellement à une situation où les êtres humains ne sont pas tous égaux en vertu de la loi et ne jouissent pas tous de la même protection. Nous croyons aussi que toute législation en matière d'homicide par compassion serait conçue à l'intention des cas difficiles comme celui de l'affaire *Latimer*. Tout en reconnaissant les difficultés que pose, en l'occurrence, la condamnation du meurtrier, nous estimons que les cas difficiles sont garants de lois fautives. En modifiant le Code criminel de manière à traiter ces cas difficiles, nous ferions place aussi à toute une gamme de nouveaux problèmes bien pires que le dilemme actuel.

Pour illustrer les problèmes auxquels donnerait lieu l'inscription au Code criminel d'une exception pour homicide par compassion, attardons-nous à deux modifications possibles du Code criminel qui auraient pour effet d'inscrire dans la loi l'homicide par compassion. La première option serait l'insertion au Code criminel d'une exemption pour homicide par compassion, défini en termes généraux, qui s'appliquerait à tout homicide dont l'auteur pourrait prétendre, preuve raisonnable à l'appui, qu'il a agi par compassion. Cela entraînerait la création d'une troisième catégorie de meurtre, l'homicide par compassion, abolissant la peine minimale seulement pour un homicide motivé par la compassion ou par la pitié. Cette approche entraînerait deux sortes de problèmes.

En premier lieu, la motivation n'est pas observable. La motivation d'un acte ne peut s'établir de la même façon que les faits entourant cet acte. En droit canadien, deux principes accentuent cette vérité: la culpabilité doit être prouvée au-delà de tout doute raisonnable, et on ne peut obliger un accusé à témoigner à son propre procès. Par conséquent, dès que la défense prétendrait que son client a agi par compassion, la poursuite serait tenue de prouver au-delà de tout doute raisonnable que le motif n'était pas la compassion, et cela, sans avoir la possibilité d'interroger l'accusé devant le tribunal. Nous verrions ainsi surgir un nombre exagéré d'affaires censées relever de l'homicide par compassion. Des parents ou des amis ayant tué un être cher qui était âgé, handicapé ou incapable, mais riche, pourraient prétendre avoir agi par compassion. Il serait alors très difficile de prouver qu'ils ont plutôt agi par cupidité.

En second lieu, la compassion peut être définie en termes très généraux. Qu'est-ce que la compassion? Dans quelles situations peut-on envisager qu'elle puisse servir de motif à un homicide? Sur Internet, à l'adresse [www.dictionary.com](http://www.dictionary.com), nous avons trouvé les trois définitions suivantes de la compassion:

Premièrement, conscience profonde de la souffrance d'un autre, accompagné du désir de la soulager.

Voir «pitié» pour synonyme.



Literally, suffering with another; a sensation of sorrow excited by the distress or misfortunes of another; pity; commiseration.

The third entry defined compassion as:

a deep awareness of and sympathy for another's suffering; the humane quality of understanding the suffering of others and wanting to do something about it.

Again, pity is a synonym.

Since compassion is usually linked to the suffering of another person, what kinds of suffering would be viewed as worthy of a lesser sentence when the suffering is relieved by killing? Would our courts be capable of limiting it to cases of physical suffering when mental, emotional, spiritual and psychological suffering are equally devastating? What about the depressed? Is their mental suffering not equal to the physical suffering of others? We are concerned about those persons because their cries for help might be mistaken for requests for death.

After years of precedent-setting court decisions, the application of compassionate homicide might expand into a myriad of situations. I use these examples: Would a poor mother who drowns her newborn out of compassion for the child based on its prospects of a low quality of life qualify for a compassionate exemption from the minimum sentence? What about a teenager who dumps her newborn in the garbage because she did not want it anyway? Would both of them have grounds to be treated under the compassionate homicide law? Would the compassionate homicide law be abused by defendants who are exceptionally skilled at spinning an emotional web in the courtroom, or would it just be abused by killers who are wealthy and capable of affording the best possible legal defence? Would this further add to the problem of unequal treatment for poor and marginalized people in society?

We can imagine the possible abuses that could occur if a broadly defined compassionate homicide law were reality, but we can also recognize the new difficulty that would occur for the prosecution to prove that the defence was inappropriately using a compassionate grounds defence for a murderer who wished to receive less than a minimum sentence. We believe that the Special Senate Committee on Euthanasia and Assisted Suicide included within its recommendation that the essential elements of compassion and mercy must be clearly and narrowly defined in order to limit the cases in which a less stringent sentence would be available, because it recognized the pitfalls of a broadly defined definition of compassion.

We examined this first option so that we could compare it to the second option, the one that the Senate committee is proposing, which is a narrowly defined compassionate homicide exemption in the Criminal Code applied only to homicides where proof exists beyond a reasonable doubt that the victim was suffering and the act was compassionately motivated. There are two serious problems with this approach.

Deuxièmement, littéralement, souffrir avec un autre, sentiment de tristesse provoqué par la détresse ou les malheurs de quelqu'un d'autre; pitié; commisération.

Dans un troisième cas, la compassion était définie comme suit:

Profonde conscience des malheurs d'un autre et sympathie à son égard; aptitude à comprendre la souffrance de quelqu'un et désir de faire quelque chose à cet égard.

On donnait encore la pitié comme synonyme.

Puisque la compassion est normalement liée à la souffrance d'une autre personne, quelle sorte de souffrance serait censée mériter une peine moins sévère lorsqu'un meurtre l'aurait soulagée? Comment les tribunaux pourraient-ils limiter cette souffrance au domaine physique alors que la souffrance mentale, émotive, spirituelle et psychologique est tout aussi dévastatrice? Que penser des personnes déprimées? Leurs souffrances mentales ne sont-elles pas équivalentes aux souffrances physiques d'un autre? Nous nous intéressons aux déprimés parce que leurs appels au secours peuvent être confondus avec une demande de mourir.

Après des années d'établissement de précédents par les tribunaux, la mise en application de l'homicide par compassion pourrait déboucher sur une foule de situations. La pauvre mère qui aurait noyé son nouveau-né par compassion, devant ses perspectives d'une qualité de vie misérable, serait-elle admissible à l'exemption de la peine minimale au titre de la compassion? Que dire de l'adolescente qui aurait déposé son nouveau-né dans une poubelle parce qu'elle n'en voulait tout simplement pas? Les deux pourraient-elles s'attendre à être traitées selon les dispositions en matière d'homicide par compassion? Y aurait-il recours abusif à ces dispositions de la part d'accusés particulièrement habiles à susciter les émotions dans une cour de justice ou seulement de la part de meurtriers ayant les moyens de se payer les meilleurs avocats? Les inégalités que la société fait subir aux pauvres et aux marginaux en seraient-elles encore exacerbées?

On imagine bien les abus auxquels pourrait donner lieu une définition législative vague de l'homicide par compassion, mais reconnaissons aussi la difficulté de la poursuite si elle devait prouver que la défense invoque à mauvais escient le motif de la compassion en faveur d'un assassin qui veut échapper à la peine minimale. Il est vrai que le comité sénatorial spécial sur l'euthanasie et l'aide au suicide a inscrit parmi ses recommandations que les éléments essentiels de compassion ou de pitié doivent être clairement et strictement définis afin de limiter les cas admissibles à une peine moins sévère, conscient qu'il était du danger que représentait une définition trop vague de la compassion.

Nous avons examiné cette première option d'abord pour pouvoir la comparer à la seconde, celle que propose le comité sénatorial. Il s'agit ici de l'insertion au Code criminel d'une exemption relative à l'homicide par compassion, défini strictement, qui s'appliquerait uniquement aux homicides pour lesquels la preuve a été faite au-delà de tout doute raisonnable que la victime souffrait et que l'acte a été motivé par la compassion. Cette approche entraînerait deux graves problèmes.

The first problem is that this approach shares the same problems as the more broadly defined compassionate homicide law for the prosecutor to disprove a claim of compassionate motivation. The problem of being unable to observe or prove motivation remains. The problem of the definition of compassion still exists. The problem of precedent-setting court cases widening the interpretation of compassionate homicide still exists. In fact, all the arguments apply here as in the more broadly defined law, except that the cases have simply been restricted to a more particular group of victims.

The second problem is that it assumes that if someone kills a person who happens to have a severe disability, claims of compassion may be believable in a court of law and the burden of proof will be with the prosecutor to prove otherwise. Therefore, murderers of disabled or other vulnerable people, whether the victims are physically disabled, mentally incompetent, emotionally or psychologically unfit, or age impaired, will be treated differently than murderers of otherwise healthy people, even if their acts are identical. This is particularly distressing given that there is significant proof already that people with disabilities and other vulnerable persons already experience higher rates of violent attacks against them and that vulnerable people in general are not valued equally as dignified, otherwise healthy members of our society.

We believe that the disabled and otherwise vulnerable persons in society are not in need of less protection in society but in fact of more protection. We are also under the opinion that any compassionate homicide law, even if narrowly defined, will result in a challenge to its constitutionality and will be struck down by the Supreme Court of Canada based on providing lesser protection for citizens with disabilities than for other citizens. Section 15 of the Charter of Rights and Freedoms states that:

Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

When examining the report "Of Life and Death," the primary reason given to suggest that lesser sentences are necessary for cases of compassionate homicide seems to be summed up in this type of argument: Since it is difficult to convict cases of euthanasia under first or second degree murder because the prosecutor and jury believe the mandatory minimum sentences are too harsh, a less severe penalty should be imposed in cases where an element of compassion or mercy is involved. The comment that best exemplifies that reasoning was made by Professor Bernard Dickens of the Faculty of Law at the University of Toronto when he explained:

The limitation of the existing murder provision is that by the Criminal Code the minimum punishment for murder is life imprisonment. We distinguish first degree murder from second degree murder not by reference to the sentence but by

En premier lieu, cette approche présenterait les mêmes difficultés qu'une définition en termes plus vagues de l'homicide par compassion pour la poursuite obligée de réfuter la thèse du motif de compassion. L'incapacité d'observer ou de prouver le motif serait toujours là. Le problème lié à la définition de la compassion serait toujours là. Et l'établissement de précédents judiciaires ayant pour effet d'élargir l'interprétation de l'homicide par compassion serait également toujours là. En fait, les arguments attribuables à une définition législative trop vague s'appliquent également ici, sauf qu'on aura limité les cas à un groupe de victimes particulier.

En second lieu, on suppose que dans le cas du meurtre d'une personne souffrant d'une incapacité grave, un tribunal pourrait admettre l'invocation du motif de compassion, et il appartiendrait à la poursuite de faire la preuve du contraire. Par conséquent, le meurtre d'une personne handicapée ou vulnérable, qu'il s'agisse d'une personne frappée d'un handicap physique, d'une incapacité mentale, de troubles émotifs ou psychologiques, de difficultés dues au vieillissement, sera traité différemment du meurtre d'une personne en santé même s'il s'agit d'actes identiques. La chose est particulièrement troublante quand on sait combien le taux d'agression à l'égard des personnes handicapées ou vulnérables est élevé et que, en général, les personnes vulnérables ne jouissent pas d'une dignité égale au sein de la société.

Nous estimons que les personnes handicapées et vulnérables ont besoin non pas d'être moins protégées par la société, mais de l'être encore mieux. Nous sommes également d'avis que les dispositions législatives, même strictement définies, en matière d'homicide par compassion seraient contestées du point de vue constitutionnel et invalidées par la Cour suprême du Canada, laquelle jugerait qu'elles accordent aux citoyens ayant une déficience moins de protection qu'à l'ensemble des citoyens. L'article 15 de la Charte canadienne des droits et libertés se lit ainsi:

La loi ne fait acception de personne et s'applique également à tous, et tous ont droit à la même protection et au même bénéfice de la loi, indépendamment de toute discrimination, notamment des discriminations fondées sur la race, l'origine nationale ou ethnique, la couleur, la religion, le sexe, l'âge ou les déficiences mentales ou physiques.

Dans le rapport «De la vie et de la mort», la principale raison invoquée pour l'imposition d'une peine moins sévère en cas d'homicide par compassion semble pouvoir se résumer ainsi: puisqu'il est difficile dans les cas d'euthanasie d'obtenir une condamnation pour meurtre au premier ou au second degré parce que les poursuivants et les jurys estiment la peine minimale trop sévère, il faudrait par conséquent imposer une peine moins sévère dans les cas où il existe un élément de compassion ou de pitié. Les propos qui illustrent le mieux ce raisonnement sont ceux du professeur Bernard Dickens, de la Faculté de droit de l'Université de Toronto. Citons-les:

Le problème que soulève dans ce cas la disposition relative au meurtre, c'est qu'en vertu du Code criminel la peine minimale pour le meurtre est l'emprisonnement à perpétuité. Le meurtre au premier degré se distingue du meurtre au



reference to eligibility for parole; that is, those convicted of first degree murder cannot, with exceptions, be eligible for parole in less than 25 years. Those convicted of the only alternative, second degree murder, are not eligible for release in less than 10 years. Prosecutors at times seem to find this too harsh, and juries again seem to have reservations about imposing sentences they consider excessive.

We recognize that this argument might be used to defend the lives of vulnerable persons by stating that if you kill a disabled person, even with a compassionate motive, you will be punished, even if it is a lesser punishment, but we also recognize in practice that people who kill another person, even with a compassionate motive, tend not to do it with the intent of getting caught. Thus, when they are caught, the use of a compassionate homicide law will become the recourse to getting the least possible sentence for the crime.

We are also concerned with the argument that the sentence is too harsh and therefore it is difficult to convict. Since prosecutors and juries do not seem to have a problem with giving the mandatory minimum sentence for murdering an otherwise healthy person, that argument advances the belief of the disability community that their lives are less valued by society. We believe that because the disabled, the elderly, the chronically ill, the depressed and other vulnerable persons are often dependent on a trust relationship with their caregivers, they are probably in need of more protection rather than less protection by the courts.

To prove our point, we decided to look at the Internet again, at [www.dictionary.com](http://www.dictionary.com), where we found two definitions of vulnerable. The first source defined vulnerable as susceptible to physical injury; susceptible to attack; open to censure or criticism; assailable; and likely to succumb, as to persuasion or temptation. The second defined it as susceptible to attack; susceptible to criticism or persuasion or temptation; capable of being wounded or hurt; and susceptible to physical or emotional injury.

That would imply that vulnerable people are particularly susceptible to being hurt, used, abused or, in this case, killed, even for compassionate reasons. A natural conclusion for this committee would be that, in a just state, the vulnerable must be specially protected due to their having special needs. When we recognize an area where the vulnerable are not being effectively protected, then it becomes incumbent upon lawmakers to further those protections to ensure that abuses are not occurring. The fact that they are vulnerable implies that they are incapable of effectively defending themselves, therefore government must specially protect them. To suggest lesser sentences for people who kill disabled or other vulnerable people implies the opposite of

second degré non pas par la peine imposée, mais pour ce qui est de l'admissibilité à la libération conditionnelle: les personnes déclarées coupables de meurtre au premier degré ne peuvent, sauf exception, être admissibles à la libération conditionnelle avant d'avoir purgé 25 ans de prison. Les personnes déclarées coupables de meurtre au deuxième degré, la seule autre possibilité, ne sont pas admissibles à la libération avant 10 ans. Il arrive que les poursuivants trouvent que ces peines sont trop sévères, et le jury semble souvent réticent à imposer des peines qu'il considère comme excessives.

Nous reconnaissons la possibilité d'invoquer cet argument pour défendre la vie de personnes vulnérables, en faisant valoir que quiconque tue une personne handicapée, même par compassion, sera punie même si la peine imposée est moins sévère. Toutefois, en pratique, quiconque tue une autre personne, même par compassion, n'a pas tendance à vouloir se faire attraper. Par conséquent, lorsqu'elles seront attrapées, ces personnes voudront tout normalement invoquer les dispositions en matière d'homicide par compassion afin d'obtenir la peine la moins sévère possible pour leur crime.

Nous nous inquiétons aussi de l'argument selon lequel il est difficile d'obtenir une condamnation parce que la peine est trop sévère. Puisque les poursuivants et les jurys ne semblent pas avoir de difficulté à imposer la peine minimale pour le meurtre d'une personne en santé, l'argument laisse entendre aux personnes qui souffrent d'une incapacité que leur vie est moins précieuse pour la société. Nous estimons que, parce que les personnes handicapées, les vieillards, les malades chroniques, les personnes déprimées et toute personne vulnérable dépendent souvent d'une relation de confiance avec ceux qui les soignent, ils ont probablement besoin non pas d'être moins protégés par les tribunaux mais de l'être davantage.

Pour le démontrer, nous sommes allés encore une fois chercher sur l'Internet, à l'adresse [www.dictionary.com](http://www.dictionary.com), les deux définitions suivantes du terme «vulnérable». La première définition donnait: qui peut être blessé; qui peut être facilement atteint; sensible à la censure ou à la critique; qui peut être agressé; et qui peut succomber, comme à la persuasion ou à la tentation. La deuxième définition donnait: qui peut être facilement atteint; sensible à la critique, à la persuasion ou à la tentation; qui peut être blessé; et susceptible de subir des blessures physiques ou émotives.

C'est donc dire que les personnes vulnérables sont particulièrement susceptibles d'être blessées, exploitées, abusées, voire assassinées, même par compassion. Il serait naturel pour les membres du comité de conclure que dans une société juste il convient d'accorder aux personnes vulnérables une protection spéciale en raison de leurs besoins particuliers. S'il existe un domaine qui révèle un manque de protection à l'égard des personnes vulnérables, il appartient alors aux législateurs de veiller à mieux les protéger de tout abus. Puisque leur vulnérabilité les rend incapables de bien se défendre, le gouvernement se doit de leur offrir une protection spéciale. L'idée d'imposer une peine moins sévère à ceux qui auront tué une



what a just society should be proposing, because it results in less protection for those who need it most.

In our introduction we referred to the recommendation regarding lesser sentences for those who participate in voluntary euthanasia. We consider that recommendation to be part of our concern in relation to compassionate homicide because it would also create a situation where there is less protection for the disabled, the elderly, the chronically ill, the depressed and other vulnerable persons. If someone is caught in the act of euthanasia, they will instantly claim it to be a case of compassionate homicide. How can this be proven? Unethical caregivers who take the power of death into their hands may choose to kill others because they have decided the time has come for those people to die. If a compassionate homicide law existed, it would be difficult to prove beyond reasonable doubt that those people did not request death or that those people were depressed and crying for help.

We believe that, even in the case of lesser sentences for voluntary euthanasia, the disabled and other vulnerable persons would have less protection under the law. That would result in more deaths for supposed compassionate motives of the elderly, the disabled, the chronically ill and other vulnerable persons.

In our introduction we also referred to the committee's recommendation concerning the withholding or withdrawal of artificial hydration and nutrition as treatment. The withholding and withdrawal of them is in some circumstances as successful as the withholding and withdrawal of artificial respiration, blood transfusions and CPR, and is connected to compassionate homicide. The reason we connect this recommendation to compassionate homicide is that unethical family members, friends and medical caregivers could use the licence of this recommendation to starve an incompetent person to death, especially when the incompetent person is persistently living or costing others too much, either by monetary, emotional, psychological or social means.

There are several modern examples of unethical caregivers who are responsible for the deaths of many of their incompetent patients. Since the release in June 1999 of the new British Medical Association guidelines on withdrawal and withholding of assisted feeding, more than 60 cases that have been reported to the authorities and are now being investigated maintain that patients are being denied food and drink with the intention of causing them to die. The proportion of abuse that has arisen in Britain in such a short period of time has led to the House of Lords condemning, on December 15, 1999, the withholding of food and drink from patients. It has led to the successful introduction of Mrs. Ann Winterton's Medical Treatment (Prevention of Euthanasia) Bill in the British House of Commons.

personne handicapée ou vulnérable va à l'encontre de ce que devrait proposer une société juste, parce que cela consiste à moins bien protéger ceux qui ont le plus besoin de protection.

Nous avons fait allusion tout à l'heure à la recommandation qui consiste à réduire la peine de quelqu'un qui aurait pris part à une euthanasie volontaire. Notre inquiétude relative à l'homicide par compassion englobe aussi cette recommandation qui déboucherait sur une situation telle que les personnes handicapées, les vieillards, les malades chroniques, les personnes déprimées ou vulnérables de quelque façon que ce soit s'en trouveraient moins bien protégées. Quiconque serait pris en flagrant délit de commettre l'euthanasie prétendrait aussitôt avoir agi par compassion. Comment le prouver? S'arrogeant le pouvoir de vie ou de mort, des soignants dépourvus de tout sens moral pourraient décider que le moment est venu pour telle ou telle personne de mourir et, donc, de l'assassiner. Si l'homicide par compassion était inscrit dans la loi, il serait alors très difficile de prouver au-delà de tout doute raisonnable que la personne décédée n'a pas réclamé la mort ou n'était pas déprimée et n'a pas lancé d'appel au secours.

Nous pensons que même l'imposition d'une peine moins sévère pour l'euthanasie volontaire aurait pour effet d'offrir une moins bonne protection législative aux personnes handicapées ou vulnérables. Nous verrions alors augmenter le nombre de morts dites par compassion parmi les personnes handicapées ou vulnérables, les vieillards, les malades chroniques, et cetera.

Nous avons également associé tout à l'heure à l'homicide par compassion la recommandation selon laquelle le comité considère que l'hydratation et l'alimentation artificielles sont des traitements; par conséquent, il est aussi acceptable, dans certaines circonstances, de ne pas les administrer ou de les interrompre que de ne pas administrer ou d'interrompre la respiration artificielle, les transfusions sanguines ou la réanimation cardiorespiratoire. La raison pour laquelle nous associons cette recommandation à l'homicide par compassion, c'est que des personnes dépourvues de sens moral, membres de la famille, amis ou fournisseurs de soins, pourraient s'en prévaloir pour affamer jusqu'à ce que mort s'ensuive une personne frappée d'incapacité, en particulier si cette personne s'acharne à vivre contre la volonté des autres ou coûte trop cher aux autres, compte tenu de leurs moyens financiers, émotifs, psychologiques ou sociaux.

Il existe de nombreux exemples modernes de «soignants» qui, sans aucun sens moral, ont causé la mort d'un grand nombre de malades frappés d'incapacité. Depuis la parution en juin 1999 des nouvelles lignes directrices de la British Medical Association touchant l'interruption ou la suppression de l'alimentation artificielle, plus de 60 allégations touchant des malades privés de boire et de manger dans l'intention de causer leur mort ont été signalées aux autorités et font l'objet d'une enquête. La hausse soudaine des cas d'abus en si peu de temps, en Grande-Bretagne, a amené la Chambre des lords à condamner, le 15 décembre 1999, la suppression de l'alimentation et de l'hydratation des malades et entraîné le dépôt, à la Chambre des communes, d'un projet de loi portant sur les soins médicaux (prévention de l'euthanasie), parrainé par Mme Ann Winterton.

That may seem like an interesting claim. However, if you consider the facts, you will recognize how the withdrawal of assisted feeding can lead to the intended death of incompetent patients. For instance, on December 2, 1999, the family of Florence LaDouceur filed a lawsuit against the Villa Maria nursing home in Windsor, Ontario, for attempting to starve and dehydrate their mother when she was 93 years old. Mrs. LaDouceur did not have a terminal condition. She was capable of eating and drinking with normal assistance. Her daughter Thelma, who had the power of attorney for her mother's personal care, was not consulted in the decision to stop providing normal food and fluids for her mother. Florence LaDouceur lived at the Villa Maria between October 26, 1998, and March 14, 1999. Her family removed her from the nursing home and brought her to the Hotel Dieu/Grace Hospital where she was fed, rehydrated and treated for pneumonia. She was very near to death when arriving at the hospital. She was discharged from the hospital and moved into the home of her daughter Thelma on March 22 — some eight days later — where she had made almost a complete recovery. The lawsuit was brought by the family to set a precedent that it is wrong to injure or kill people through starvation or dehydration and to redress the damages that were done to their mother. Even though Florence LaDouceur died on January 14, 2000, the lawsuit is continuing in her memory to protect the lives of other vulnerable people who are dependent on institutional care.

We believe that it is important to define medically assisted nutrition and hydration as normal care and not as treatment. The reason is that in common law it is properly recognized that a patient can always refuse treatment or request that treatment be withheld or withdrawn, especially when it becomes futile or particularly burdensome. Defining assisted feeding as treatment opens the door to its withdrawal from incompetent patients who are not otherwise dying. Abuses can run rampant, and vulnerable people will be killed without their consent. One of the most horrific ways to die is through starvation and dehydration.

When assisted feeding is defined as normal care, then the measure of feeding is based on want or need. If a patient is dying and has little need for assisted feeding, then he or she would receive a minimal feeding. If the patient has no need for assisted feeding, usually due to nearing the end of life, then assisted feeding would cease. We recognize that not all family members, friends and medical caregivers are ethically motivated. Therefore, we advocate protections for the vulnerable, rather than lesser protections.

If medically assisted nutrition and hydration is defined as medical treatment, the preferred way of removing persistently living incompetent patients from financially strapped nursing homes and medical care facilities will be through the withdrawal and withholding of assisted feeding. The excruciating symptoms experienced by starving people will be covered up by analgesics and death will be recorded as being from natural causes. The vulnerable will be given a life sentence rather than cared for in a dignified manner until their dying day. Compassionate homicide would thus be unofficially approved within policy in Canada.

Aussi intéressante que puisse paraître cette affirmation, la réalité nous montre que l'interruption de l'alimentation artificielle peut mener à la mort volontaire de patients dans l'incapacité de décider. Par exemple, le 2 décembre 1999, les enfants de Florence LaDouceur ont intenté une poursuite contre le centre d'accueil Villa Maria de Windsor, en Ontario, pour avoir tenté de priver d'alimentation et d'hydratation leur mère, Florence, âgée de 93 ans. Mme LaDouceur n'avait pas de maladie terminale, elle était en mesure de boire et de manger avec l'aide normale de quelqu'un d'autre, et sa fille, Thelma, ayant le titre de procureur aux soins de la personne, n'avait pas été consultée avant que la décision ne soit prise de cesser d'alimenter et d'hydrater sa mère. Mme LaDouceur a vécu au centre Villa Maria du 26 octobre 1998 au 14 mars 1999. Sa famille l'a retirée du centre d'accueil pour la confier à l'hôpital Hôtel-Dieu/Grace, où elle a été alimentée, réhydratée et soignée pour une pneumonie. Elle était à l'article de la mort à son arrivée à l'hôpital. Le 22 mars, elle a obtenu son congé pour aller vivre chez sa fille, Thelma, où elle a pu se rétablir presque complètement. La famille a entamé cette poursuite afin de créer un précédent destiné à montrer qu'on ne peut impunément causer du tort à quelqu'un ou le tuer en l'empêchant de s'alimenter ou de s'hydrater, et pour obtenir réparation pour le tort causé à Mme LaDouceur. Cette dernière est décédée le 14 janvier 2000, mais la poursuite suit son cours pour honorer sa mémoire et protéger la vie d'autres personnes vulnérables qui dépendent des soins reçus en institution.

Il importe, à notre avis, de considérer l'hydratation et l'alimentation artificielles en milieu médical non pas comme un traitement, mais comme des soins ordinaires. En effet, la common law reconnaît à juste titre à un malade le droit de refuser un traitement ou d'exiger sa suspension ou son interruption, surtout lorsqu'il s'avère inutile ou trop pénible. Le fait de définir l'alimentation artificielle comme un traitement ouvrirait la voie à sa suppression dans le cas de malades frappés d'incapacité qui tardent à mourir. Les cas d'abus pourraient se multiplier, et des êtres vulnérables, seront tués sans leur consentement. Une des façons les plus horribles de mourir, c'est de mourir affamé et déshydraté.

Si l'alimentation artificielle est définie comme un traitement, son application est alors fondée sur le besoin ou la nécessité. Le mourant qui a peu besoin d'alimentation artificielle ne serait alimenté qu'au minimum. Celui qui n'a pas besoin d'alimentation artificielle parce que la fin approche verra son traitement interrompu. Étant donné que ce ne sont pas tous les parents, amis et fournisseurs de soins médicaux qui ont un sens moral élevé, nous sommes en faveur d'accroître la protection des personnes vulnérables et non de la réduire.

Si l'alimentation et l'hydratation artificielles en milieu médical sont définies en tant que traitement, le moyen privilégié de se débarrasser de malades frappés d'une incapacité permanente sera, pour un centre d'accueil ou un établissement de soins médicaux aux prises avec des difficultés financières, de supprimer leur alimentation artificielle. Le martyre du malade affamé sera atténué par des analgésiques, et sa mort sera portée au compte de causes naturelles. On aura ainsi condamné à mort un être vulnérable au lieu de le soigner jusqu'à la fin dans la dignité. L'homicide par compassion aura fait son entrée officielle dans les



resulting in abuse of our laws and our values. The only difference between intentionally starving or dehydrating a person against their wishes or using potassium chloride to kill that person is that using potassium chloride at least provides a quick death.

The Euthanasia Prevention Coalition of Ontario believes that any change to the law to allow for a compassionate homicide exemption from the mandatory minimum sentence would lead to a further erosion of protections for vulnerable people in society and would result in more killing of vulnerable persons, particularly the physically and mentally disabled, the elderly, the chronically ill and the depressed. It would also lead to abuses of the present system whereby defence lawyers, when possible, would attempt to put forward a plea of compassionate homicide with the hope of lessening the sentence for their clients or to shift the burden of proof to a greater level to the prosecution. It would create a two-tier system in which those who kill vulnerable persons will be treated more leniently than those who kill otherwise healthy people. It would also result in an expensive challenge to the Supreme Court of Canada based on the provisions of section 15 of the Charter of Rights and Freedoms.

We believe that the Government of Canada should not create a new compassionate homicide law but, rather, should introduce a policy of stricter sentences for people who kill vulnerable persons, particularly the physically and mentally disabled, the elderly, the chronically ill and the depressed. That would establish a precedent that vulnerable people have special needs and therefore need special protection. It would also remind unethical family members, friends and medical caregivers that the trust relationship that they have must be upheld and protected and not abused.

We also believe that hospice care, palliative care and care of other vulnerable persons within Canada should be enhanced and promoted. Canada has some of the best palliative care and care for the disabled in the world. Is it not a better response to build upon the supportive and caring environment of palliative care and care for the disabled rather than lessening the sentences for those who kill the vulnerable? If the reason for killing a disabled child is the lack of care available to the parent, are we not also akin to the killing of that child?

We believe that dignity is not found in one's personal autonomy over death but, rather, in one's experience of love and caring with others. We recognize that compassion is suffering with another, but our reaction of doing something for them, of granting the other dignity, is by caring for them. True compassion leads to sharing another's pain; it does not kill the person whose suffering we cannot bear. The true test of our dignity is not how we achieve our self-actualization but, rather, how we serve the needs of others and create a society that equally respects the lives of everyone,

usages canadiens, portant ainsi atteinte à nos lois et à nos valeurs. La seule différence entre le fait d'empêcher volontairement quelqu'un de s'alimenter et de s'hydrater et le fait de le tuer avec une solution de chlorure de potassium, c'est que le chlorure de potassium assure au moins une fin rapide.

La Euthanasia Prevention Coalition of Ontario estime que toute modification de la loi en vue de permettre une exemption de la peine minimale pour homicide par compassion aurait pour effet d'éroder encore davantage la protection des personnes vulnérables au sein de la société et de hausser encore le nombre de meurtres perpétrés sur des personnes vulnérables, notamment celles qui ont un handicap physique ou mental, les vieillards, les malades chroniques et les personnes déprimées. Cela favoriserait aussi les abus commis à l'égard du système judiciaire du fait que les avocats de la défense s'efforceraient d'invoquer dans la mesure du possible l'homicide par compassion de manière à obtenir pour leur client une peine moins sévère, ou d'obliger encore davantage la poursuite à établir le fardeau de la preuve. Il en résulterait une justice à deux niveaux où ceux qui tuent une personne vulnérable seraient traités avec plus d'indulgence que ceux qui tuent des personnes en santé. Cela se traduirait aussi par de coûteuses contestations judiciaires auprès de la Cour suprême du Canada en vertu des dispositions de l'article 15 de la Charte canadienne des droits et libertés.

Selon nous, le gouvernement du Canada ne doit pas créer de nouvelle catégorie de meurtre au titre de l'homicide par compassion, mais plutôt introduire la règle de peines plus sévères pour le meurtre de personnes vulnérables, notamment celles qui ont un handicap physique ou mental, les vieillards, les malades chroniques et les personnes déprimées. Il y aurait ici un précédent d'établi, selon lequel les personnes vulnérables ont des besoins particuliers et qu'il leur faut par conséquent une protection particulière. Ceux qui, parmi les membres de la famille, les amis et les fournisseurs de soins médicaux, sont dépourvus de sens moral comprendraient aussi qu'il importe de protéger et de renforcer la relation de confiance, et non d'y porter atteinte.

Nous sommes également d'avis qu'il faut soutenir et promouvoir les soins palliatifs et les soins donnés aux personnes vulnérables, au Canada, où ces soins sont parmi les meilleurs du monde. N'est-il pas préférable de renforcer encore l'environnement humanitaire qui préside aux soins palliatifs et aux soins offerts aux personnes vulnérables plutôt que de réduire les peines imposées aux meurtriers de personnes vulnérables? Si quelqu'un tue son enfant handicapé parce qu'il ne peut pas, en tant que parent, lui procurer les soins nécessaires, ne sommes-nous pas aussi associés au meurtre de cet enfant?

Nous croyons que la dignité ne réside pas dans l'autonomie personnelle devant la mort, mais plutôt dans l'amour et la sollicitude que nous éprouvons pour les autres. Il est vrai que la compassion consiste à partager la souffrance d'une autre personne, mais la façon de faire quelque chose pour cette personne, de reconnaître sa dignité, c'est de lui procurer les soins dont elle a besoin. La véritable compassion nous amène à partager la souffrance de l'autre, et non à tuer la personne dont nous ne pouvons plus supporter la souffrance. La véritable preuve de sa



including the disabled, the dying, the suffering, the depressed and all other vulnerable persons.

**Ms Jakki Jeffs, Executive Director, Alliance for Life Ontario:** Madam Chair, I come with the thanks of our board and our 40,000 members in Ontario. I also bring to the table the voices of Manitoba, Newfoundland, Labrador and Prince Edward Island. Unfortunately, our legal counsel could not release himself from his responsibilities to be here. We generally work as a team. He speaks to the head and I speak to the heart. Thus, I am having to do both today.

First, I should like to deal specifically with compassionate homicide.

Professor Dick Sobsey said:

Failure to provide equal protection of the law is the worst form of discrimination.... Giving any lesser penalty will put thousands of people with disabilities in greater danger of death and violence.

We do not support any amendments to the Criminal Code that would provide for a less severe penalty in euthanasia cases where there is the essential element of compassion or mercy, for the following reasons: first, it would breach Parliament's duty under the Charter of Rights and Freedoms, section 15, to provide equal protection of the law to physically and cognitively impaired people; second, it would be an abdication of Parliament's responsibility to protect human life; third, it would encourage health care providers and family members upon whom vulnerable persons may depend for their very lives to contemplate the unthinkable — to kill their loved one or patient; and fourth, the parameters of appropriate compassion cannot be adequately defined to prevent widespread abuse.

Subsection 15(1) of the Charter reads as follows:

Every individual is equal before and under the law and has the right to the equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

We believe that the proposal for a lesser offence of compassionate homicide is aimed directly at people with disabilities. We can conceive of no other category of person for whom compassion could logically lead another person to conclude that they were better off dead. We wholeheartedly agree with Professor Sobsey's assessment that this proposal, if implemented, would represent the worst kind of discrimination. There is much concern these days about the Canadian health care system becoming a two-tiered system. This proposal would create a

dignité n'est pas dans la manière de se réaliser soi-même, mais dans celle avec laquelle on répond aux besoins des autres et crée une société respectueuse de la vie de chacun, notamment des personnes handicapées, des mourants, de ceux qui souffrent, des personnes déprimées et de toutes celles qui, d'une façon ou d'une autre, sont vulnérables.

**Mme Jacki Jeffs, directrice exécutive, Alliance pour la vie, Ontario:** Madame la présidente, je transmets les remerciements de notre conseil d'administration et de nos 40 000 adhérents en Ontario. Je suis également le porte-parole du Manitoba, de Terre-Neuve et du Labrador et de l'Île-du-Prince-Édouard. Malheureusement, notre conseiller juridique n'a pas pu se libérer pour nous accompagner. Normalement, nous travaillons en équipe. Il parle avec sa tête et moi avec le cœur. Aujourd'hui, je dois faire les deux.

Tout d'abord, je voudrais parler directement de l'homicide par compassion.

Le professeur Dick Sobsey a dit ceci:

Le fait de ne pas accorder la protection de la loi à tous également est la pire forme de discrimination [...]. En infligeant une peine moindre, on placera des milliers de gens handicapés devant un risque accru de mort et de violence.

Nous ne sommes pas en faveur de l'idée d'apporter des modifications au Code criminel pour prévoir une peine moindre dans les cas d'euthanasie qui comportent un élément essentiel de compassion ou de pitié, et ce, pour les raisons suivantes. Premièrement, cela serait contraire à l'obligation du Parlement, qui, aux termes de l'article 15 de la Charte des droits et libertés, doit accorder la protection égale de la loi aux personnes atteintes de déficiences mentales ou physiques; deuxièmement, le Parlement, ce faisant, abdiquerait sa responsabilité de protéger la vie humaine; troisièmement, cela inciterait les dispensateurs de soins et les membres de la famille dont dépendent les personnes vulnérables à envisager l'impensable: tuer celui ou celle qu'ils aiment ou leur patient; et, quatrièmement, les paramètres de la compassion ne sauraient être définis suffisamment pour prévenir l'abus généralisé.

Le paragraphe 15(1) de la Charte se lit ainsi:

La loi ne fait acception de personne et s'applique également à tous, et tous ont droit à la même protection et au même bénéfice de la loi, indépendamment de toute discrimination, notamment des discriminations fondées sur la race, l'origine nationale ou ethnique, la couleur, la religion, le sexe, l'âge ou les déficiences mentales ou physiques.

Nous estimons que la proposition d'imposer une peine moindre pour homicide par compassion vise directement les personnes handicapées. Nous ne voyons pas d'autres catégories de gens qui puissent logiquement faire l'objet d'une compassion incitant quelqu'un à conclure qu'il vaudrait mieux qu'ils soient morts. Nous sommes pleinement d'accord avec le professeur Sobsey, qui estime que cette proposition, si elle était concrétisée, représenterait la pire espèce de discrimination. On s'inquiète beaucoup de nos jours du risque que le système de santé canadien devienne un

two-tiered justice system: one for able-bodied and able-minded persons and one for those living with disabilities.

Thomas Jefferson once wrote:

The protection of human life, and not its destruction, is the primary purpose of good government.

More recently, the late Mr. Justice John Sopinka, speaking for the majority of the Supreme Court of Canada in the *Rodriguez* case, said:

The longstanding blanket prohibition [against assisted suicide] which fulfils the government's objective of protecting the vulnerable, is grounded in the state interest in protecting life and reflects the state policy that human life should not be depreciated by allowing life to be taken.

The compassionate homicide proposal would therefore, in our view, amount to an abdication of that state responsibility.

The proposal also reflects a very naive view of human nature and disregards the important role the law can play in influencing people to do reflexively the right thing in a time of moral crisis, as well as the societal need for moral absolutes. We agree with Professor Sobsey's comment that a lesser penalty for compassionate homicide would likely weaken the healthy societal inhibition supplied by the absolute prohibition of assisted suicide and put thousands of vulnerable persons at risk. Do we really want Canadians to go through some sort of seven-step decision-making process they learned in a values clarification class in high school in determining whether or not they feel justified in doing away with Granny or little Johnny? Or would our society be better off if most of us just refused even to contemplate the unthinkable?

In *The War Against the Family*, author William Gairdner quite eloquently explains that all well-functioning societies in history have recognized the need for automatic moral response systems. He says that:

The great moral systems of the world ... work well precisely because they provide absolute standards ... The wisdom common to such systems ... is that mankind is by nature imperfect, and the great mass of human intelligence is far too embroiled in the hurly-burly of life's voyage to embark on moral research at every street juncture; therefore, a moral compass is necessary. It is because we are often so morally blinded by the exigencies of daily life, and by our own emotions, that we lean with relief on wise moral absolutes ... After all, no great moral system in history has ever had the individual as its primary moral focus.

système à deux vitesses. Cette proposition créerait un système de justice à deux vitesses, l'un pour les gens aptes physiquement et mentalement et l'autre pour les déficients.

Thomas Jefferson écrivait:

La protection de la vie humaine, et non sa destruction, est la raison d'être de tout bon gouvernement.

Plus récemment, feu le juge John Sopinka, s'exprimant au nom de la majorité des juges de la Cour suprême du Canada, dans l'arrêt *Rodriguez*, a dit ceci:

L'interdiction générale établit de longue date, et qui répond à l'objectif du gouvernement de protéger la personne vulnérable, est fondée sur l'intérêt de l'État à la protection de la vie et traduit la politique de l'État suivant laquelle on ne devrait pas dévaloriser la valeur de la vie humaine en permettant d'ôter la vie.

Par conséquent, à notre avis, la préposition relative à l'homicide par compassion constituerait une abdication de cette responsabilité de l'État.

La proposition exprime également une vision très naïve de la nature humaine et méconnaît le rôle important que la loi peut jouer dans la mesure où elle influence les gens à faire instinctivement leur devoir en temps de crise morale, ainsi que le besoin qu'a la société d'avoir des valeurs morales absolues. Nous sommes d'accord avec M. Sobsey lorsqu'il dit qu'une peine moindre pour l'homicide de compassion aurait probablement pour effet d'affaiblir cette saine inhibition que procure à la société la prohibition absolue du suicide assisté, et de mettre en péril des milliers de personnes vulnérables. Voulons-nous vraiment que les Canadiens se soumettent à un processus décisionnel quelconque en sept étapes qu'ils auront appris dans un cours de science morale à l'école secondaire pour déterminer s'ils sont justifiés ou non de mettre un terme à la vie de grand-maman ou du petit Jeanot? Ou notre société ne se porterait-elle pas mieux si la plupart d'entre nous refusaient tout simplement de même envisager l'impensable?

Dans son oeuvre *The War against the Family*, William Gairdner explique fort éloquentement que toutes les sociétés bien organisées de l'histoire ont reconnu la nécessité d'avoir des systèmes automatiques d'intervention morale. Il écrit:

Les grands systèmes moraux du monde [...] fonctionnent bien précisément parce qu'ils comportent des normes absolues [...] la sagesse commune à de tels systèmes [...] tient au fait que l'unanimité est imparfaite par nature, et que les vastes ressources de l'intelligence humaine sont beaucoup trop occupées par les péripéties du voyage de la vie pour se soucier d'interrogation morale à tous les tournants; voilà pourquoi un compas moral est nécessaire. C'est parce que nous sommes souvent tellement aveuglés moralement par les exigences de la vie quotidienne, et par nos propres émotions, que nous nous en remettons avec soulagement à ces sages valeurs morales absolues [...] Après tout, aucun grand système moral de l'histoire n'a jamais eu l'individu comme fondement premier.



The obvious problem with a reduced penalty for compassionate homicide is that it invites people in a moral crisis over life and death to consider their own subjective opinion as to whether or not their loved one or patient is living a life worth living. To recognize that this is a recipe for disaster is only to accept the reality that the human capacity for self-deception and rationalization of one's own immoral behaviour is virtually limitless, especially when self-interest becomes part of the equation.

This concern was perhaps best articulated by Mr. Justice McKenzie in the well-known case of *Stephen Dawson*, decided in 1983. He said:

I cannot accept [the parents'] view that Stephen would be better off dead ... This would mean regarding the life of a handicapped child as not only less valuable than the life of a normal child, but so much less valuable that it is not worth preserving. I tremble at contemplating the consequences if the lives of disabled persons are dependent upon such judgments.

We also tremble at the consequences. We recognize that keeping the law as it is is no panacea. The *Dawson* case, the *Latimer* case, and the more recent case of Lisa Thompson, who was given a mere slap on the wrist by the courts for attempting to kill her disabled child, prove that the law alone cannot induce everyone to do the "right thing" in times of emotional and moral stress. However, we believe that the law as it remains a useful tool in holding back the tide of moral relativism in our culture.

Finally, it is our position that any proposed parameters for the lesser penalty for compassionate homicide would not be effective in preventing widespread abuse. In 1994, the British House of Lords' Report of the Select Committee on Medical Ethics concluded as follows:

We have considered suggestions that, although deliberate killing should remain a criminal offence, killing to relieve suffering (that is deliberate killing with a merciful motive) should not be murder but that a new offence of "mercy killing" should be created. At present the offence of murder embraces acts of deliberate killing which vary enormously in their character and which most people would agree vary "in degree of moral guilt." The significant question however is whether the law could or should make a distinction between them. We consider that it should not. To distinguish between murder and "mercy killing" would be to cross the line which prohibits any intentional killing, a line which we think it is essential to preserve. Nor do we believe that "mercy killing" could be adequately defined, since it would involve determining precisely what constituted a compassionate motive. For these reasons we do not recommend the creation of a new offence.

Le problème évident que pose une peine réduite pour homicide par compassion tient au fait qu'on invite des gens, qui sont plongés dans une crise morale où la vie et la mort sont en jeu, à tenir compte de leur opinion subjective pour ce qui est de savoir si leur être cher ou le patient vit une vie digne d'être vécue. Reconnaître que c'est là courir au désastre, c'est seulement admettre la réalité que l'être humain dispose de capacités sans limite pour se mentir et justifier son propre comportement immoral, particulièrement lorsqu'il y trouve son compte.

Dans le jugement bien connu *Stephen Dawson*, qui a été rendu en 1983, le juge McKenzie a exprimé cette inquiétude mieux que personne. Il écrivait:

Je ne peux pas admettre l'idée [des parents] que Stephen serait mieux mort [...] ce serait considéré que la vie d'un enfant ayant un handicap a non seulement moins de valeur que la vie d'un enfant normal, mais qu'elle ait de si peu de valeur qu'il ne vaut pas la peine de la préserver. Je tremble à l'idée des conséquences qui s'en suivraient si la vie des personnes ayant un handicap tenait à de telles considérations.

Nous tremblons nous aussi à cette idée. Nous comprenons bien que la loi telle qu'elle est n'est pas une panacée. L'affaire *Dawson*, l'affaire *Robert Latimer* et celle plus récente de Lisa Thompson, qui a été punie d'une petite tape sur les mains par les tribunaux pour avoir tenté de tuer son enfant handicapé, prouvent que la loi à elle seule ne peut inciter à faire ce qu'on doit dans les moments de stress émotif et moral. Mais nous croyons que la loi, telle qu'elle est, reste un instrument utile pour retenir la vague de relativisme moral de notre culture.

Enfin, nous estimons que les paramètres proposés pour une peine moindre en cas d'homicide par compassion ne pourraient, quels qu'ils soient, prévenir un abus généralisé. En 1994, la Chambre des lords britannique, dans le «Report of the Select Committee on Medical Ethics», a conclu ce qui suit:

Nous avons considéré la proposition que, si l'homicide délibéré devait rester un délit criminel, l'homicide en vue de soulager la souffrance (c'est-à-dire l'homicide délibéré relevant d'un motif compatissant) ne devrait pas être considéré comme un meurtre, mais qu'il faudrait créer une nouvelle infraction désignée comme «homicide par compassion». À l'heure actuelle, le délit de meurtre englobe des actes d'homicide délibérés dont le caractère varie énormément et dont la plupart des gens diraient qu'ils varient «en degré de culpabilité morale». La question importante est donc de savoir si la loi peut ou doit faire une distinction entre ces actes. Nous estimons qu'elle ne le doit pas. Faire une distinction entre le meurtre et l'«homicide par compassion» reviendrait à franchir la limite où est interdit tout homicide volontaire, et nous pensons qu'il est essentiel de maintenir cette limite. Nous ne croyons pas non plus qu'il soit possible de définir correctement l'«homicide par compassion», puisqu'il faudrait déterminer précisément en quoi consiste un motif de compassion. C'est pour ces motifs que nous ne recommandons pas la création d'une nouvelle infraction.



We endorse those comments of the British House of Lords. Just as in the case of proposals to legalize physician-assisted suicide, to think that adequate safeguards can be built into such a system is utopian folly. As someone once said, "No society in history has ever been successful at holding the line at 'a little' killing."

If I may, I will appeal to your hearts for the last five minutes of my presentation. In Appendix A, you will see a colleague and very dear friend of mine, Mark Pickup. In today's society, Mark would be, like those who have disabilities of one sort or another, defined by what he cannot do. However, I will introduce to you a family man, a man who in 1984 was diagnosed with multiple sclerosis, a man who is an active anti-euthanasia activist. He has a heart for life. If he were here today, Mark would tell you that he is only here because his wife valued him when he did not value himself. He would explain to you that people need time to grieve, cry, and say outrageous things without being held to death wishes, and that after a period of adjustment most of them rediscover the joy of living. He would tell you, as he said to the committee in 1995:

I ask that we resist this present darkness of entertaining euthanasia and assisted suicide as a solution. Civilized societies have no place for that. Let us stop all this talk of killing and recommit ourselves to each other, to life, to independence.

He would reflect with you and tell you that this is a scary time to be a person with a disability in North America. His question to us is this: "Will I be welcome in society?"

He would state strongly that he was no less a man after years of degenerative disability than before. He said that his humanity remained intact because he bore the image of God; neither disability, dementia, deformity, incurable illness nor age would strip that image from him. Next year he might be bedridden or paralyzed, but he felt that no one could disenfranchise him from his rightful place as a creation of God.

As you look through that section, you will come face to face with children who have been killed in this country because people did not value their lives. For their sake, for the sake of justice, we must not allow our law to be changed to give anyone the right to take the life of those who are considered less than those of us who are able-bodied. We cannot allow that law to be changed.

In the interest of time, I will close, but without really saying everything I wanted to say. For children like Katie Lynn Baker, who was starved to death and neglected by her mother, for Antoine Blais, who was drowned by his mother, for Tracy Latimer, whose father, for 11 days, checked out different ways that he would kill her, whether he would shoot her, burn her or give her Valium, for children like Lisa Thompson, whose mother attempted to give her an overdose of barbiturates, for the police

Nous entérinons ces remarques de la Chambre des lords britannique. Comme dans le cas des propositions visant à légaliser le suicide médical assisté, nous estimons qu'il est illusoire de penser qu'on puisse bâtir des garde-fous suffisants dans un système de ce genre. Comme l'a dit quelqu'un un jour: «Aucune société dans l'histoire des hommes n'a jamais réussi à déterminer la limite entre tuer et tuer «un peu.»

Si vous me le permettez, j'aimerais faire appel à votre bon cœur pour les cinq dernières minutes de mon exposé. À l'annexe A, il est question d'un collègue et très bon ami à moi, Mark Pickup. Dans la société d'aujourd'hui, comme ceux qui ont un handicap d'un type ou d'un autre, Mark serait défini par ce qu'il ne peut pas faire. Cependant, je voudrais vous présenter un homme marié, un homme qui a été diagnostiqué en 1984 comme souffrant de sclérose en plaques, un homme qui milite activement contre l'euthanasie. Il a la vie à cœur. S'il était ici aujourd'hui, Mark vous dirait qu'il est ici seulement parce que sa femme le valorisait alors que lui ne se valorisait pas. Il vous expliquerait que les gens ont besoin de temps pour avoir de la peine, pleurer et dire des choses excessives sans être obligés de souhaiter la mort, et qu'après une période d'ajustement la plupart d'entre eux redécouvrent la joie de vivre. Il vous dirait, comme il l'a dit au comité en 1995:

Je demande que l'on résiste à cette idée noire actuelle d'envisager l'euthanasie et l'aide au suicide comme une solution. Il n'y a aucune place dans les sociétés civilisées pour une telle chose. Arrêtons de parler de tuer et reformulons notre engagement les uns à l'égard des autres, à l'égard de la vie, à l'égard de l'indépendance.

Il vous dirait que cela fait peur à l'heure actuelle d'être handicapé en Amérique du Nord. La question qu'il nous pose est la suivante: «Est-ce que je serai le bienvenu dans la société?»

Il vous dirait qu'il n'est pas moins un homme maintenant qu'auparavant après des années de maladie dégénérative. Il a dit que son humanité demeurerait intacte parce qu'il portait l'image de Dieu: aucun handicap, aucune démence, aucune difformité, aucune maladie incurable ni l'âge ne pourraient le dépouiller de cette image. L'an prochain il sera peut-être alité ou paralysé, mais il estime que personne ne pourrait le priver de la place qu'il a le droit d'occuper à titre de créature de Dieu.

En regardant cet article, vous devrez penser à tous ces enfants qui ont été tués au Canada parce que leur vie n'avait pas de valeur aux yeux de certains. En leur nom, au nom de la justice, nous ne devons pas permettre que nos lois soient modifiées pour permettre à quiconque de prendre la vie de ceux qui sont considérés comme étant moins importants que nous, qui n'avons pas de handicap. Nous ne pouvons permettre que soit changée cette loi.

Faute de temps, je vais m'arrêter, sans avoir vraiment dit tout ce que je voulais dire. Pour des enfants comme Katie Lynn Baker, morte de faim et négligée par sa mère, pour Antoine Blais, noyé par sa mère, pour Tracy Latimer, dont le père a réfléchi pendant 11 jours aux différents moyens de la tuer, avec une arme à feu, ou des valium, pour des enfants comme Lisa Thompson, dont la mère a essayé de lui donner une dose excessive de barbituriques, pour les policiers et pour les avocats qui décriront ces actes comme des

officers and for the lawyers who will talk about these acts and call them "acts of love," we throw out a challenge. I throw out that challenge in a last very short quote from Teague Johnson, and you have him in the appendix. Teague died in 1998. When Teague heard about Tracy Latimer's murder, he wrote on his spelling boards these words, and Teague was 11 at that point and had extreme cerebral palsy:

I can't walk or talk or feed myself. But I am not "suffering from cerebral palsy." I USE a wheelchair, but I am not "confined" to a wheelchair. I have pain, but I do not need to be "put out of my misery."

My body is not my enemy. It is that which allows me to enjoy Mozart, experience Shakespeare, savour a bouillabaisse feast and cuddle my Mom.

Life is a precious gift. It belongs to the person to whom it was given. Not to her parents, nor to the state. Tracy's life was hers to make of it what she could.

My life is going to be astounding.

We place before you these comments and quotes and our grave concerns for any change or any addition of a third category of homicide. We have covered all the other topics and unanimous recommendations and have tried to provide you with some of our research, including our own power of attorney for health care which you will find in the back of our presentation today. I am sorry that I will have to leave before questions, but I thank you very much for listening to us today.

**The Chairman:** Thank you, Ms Jeffs. Next we have two witnesses from the Care-in-Dying Coalition.

**Mr. Mark Cameron, Coordinator, Care-in-Dying Coalition:** The Care-in-Dying Coalition/Canadian Coalition Against Euthanasia is a coalition of 27 organizations from across Canada representing a wide variety of religious denominations, community groups and health care related organizations.

We have another category of membership, called "endorsers", that includes prominent citizens who are experts in their field, such as Dr. Ayoub, who is the medical oncologist at the Notre Dame Hospital in Montreal, professor of medicine at the Université de Montréal and McGill University, and director of teaching at the University Hospital Centre. Dr. Ayoub will offer us his perspective as a palliative care practitioner.

The coalition believes that every person has intrinsic dignity and worth and advocates compassionate, just and respectful care for persons who are dying. Those convictions lead us to oppose efforts to legalize euthanasia and assisted suicide and to strongly advocate increased access to palliative care and respectful end-of-life treatment for all persons.

The Care-in-Dying Coalition was formed in 1994 before the "Of Life and Death" report and we have closely followed the report and the reception it has received since then. In our view,

actes d'amour, nous lançons un défi. Ce défi se trouve dans une dernière et courte citation de Teague Johnson, dont vous avez la description à l'annexe. Teague est décédé en 1998. Teague avait 11 ans et était gravement atteint de paralysie cérébrale lorsqu'on lui a parlé du meurtre de Tracy Latimer. C'est alors qu'il a écrit sur son tableau d'écriture les mots suivants:

Je ne peux ni marcher, ni parler, ni me nourrir moi-même. Mais je ne «souffre» pas de paralysie cérébrale. Je me sers d'un fauteuil roulant, mais je ne suis pas «confiné» à un fauteuil roulant. J'ai de la douleur, mais nul besoin qu'on me «soulage de ma misère».

Mon corps n'est pas mon ennemi. C'est lui qui me donne le plaisir d'écouter Mozart, de connaître Shakespeare, de déguster une bouillabaisse et de câliner maman.

La vie est un cadeau précieux. La vie appartient à celui à qui elle a été donnée. Pas à ses parents, ni à l'État. La vie de Tracy était la sienne, pour qu'elle en fasse ce qu'elle pouvait.

Ma vie sera merveilleuse.

Nous vous présentons ces commentaires, ces citations et nos graves préoccupations relatives à tout changement ou à l'ajout d'une troisième catégorie d'homicide. Nous avons parlé de tous les autres sujets et des recommandations unanimes et nous nous sommes efforcés de vous présenter le fruit d'une partie de nos recherches, y compris notre procuration pour soins de santé que vous trouverez à la fin de notre mémoire. Je suis désolée d'avoir à partir avant les questions et je vous remercie beaucoup de nous avoir écoutés aujourd'hui.

**La présidente:** Merci, madame Jeffs. Nous accueillons maintenant deux témoins de la Care-in-Dying Coalition.

**M. Mark Cameron, coordonnateur, Care-in-Dying Coalition:** La Care-in-Dying Coalition/Canadian Coalition Against Euthanasia est une coalition de 27 organismes du Canada représentant toute une variété de confessions religieuses, de groupes communautaires et d'organismes s'intéressant aux soins de santé.

Nous avons une autre catégorie de membres, qui nous donnent leur soutien. Il s'agit de citoyens importants qui sont spécialistes dans leur domaine, comme le Dr Ayoub, qui est l'oncologue de l'Hôpital Notre-Dame de Montréal, professeur de médecine à l'Université de Montréal et à l'université McGill et directeur de l'enseignement au Centre hospitalier universitaire. Le Dr Ayoub nous donnera son point de vue à titre de praticien des soins palliatifs.

La coalition estime que chaque personne a sa dignité et sa valeur intrinsèques et milite pour des soins compatissants, justes et respectueux pour les mourants. Ce sont ces convictions qui nous mènent à nous opposer aux efforts visant à légaliser l'euthanasie et le suicide assisté et à réclamer fortement un accès accru aux soins palliatifs et à des traitements de fin de vie respectueux pour toute personne.

La Care-in-Dying Coalition a été créée en 1994, avant le rapport «De la vie et de la mort», et nous avons suivi de près la publication du rapport et l'accueil qu'il a reçu depuis. À notre



while there are some problematic areas in the 1995 report, it contains many excellent recommendations in the area of end-of-life care and is in many ways a landmark document with excellent research.

It is appropriate to follow up on the report and see how governments and others have responded to its unanimous recommendations. However, we are concerned that the emphasis of the report should be on the unanimous recommendations in the area of palliative care, rather than on contentious legal changes that will be seen through the lens of euthanasia and assisted suicide. Why is it that, in discussions of end-of-life issues, the euthanasia and assisted suicide tail seems to wag the palliative care dog? Put another way, why is Dr. Jack Kevorkian a household name, whereas Dame Cicely Saunders, who founded the modern palliative care hospice movement, is almost unknown outside of professional circles? Especially considering that most of us, at the end of our lives, would much rather be in the hands of a Dr. Saunders or a Dr. Ayoub than a Dr. Kevorkian.

The Care-in-Dying Coalition is glad that, in its update, the Senate has decided to concentrate on the unanimous recommendations of the "Of Life and Death" report, which contained many positive recommendations in the area of palliative care, and avoid reopening the contested debate on the euthanasia and assisted suicide issues. We hope that in writing its report the committee will maintain that balance and devote far more of its attention to the palliative care issues than to reopening possible changes to the Criminal Code.

The "Of Life and Death" report made unanimous recommendations in several important areas: palliative care, pain control and sedation, withholding and withdrawing of life-sustaining treatment, and advance directives. The Care-in-Dying Coalition supports the vast majority of the report's recommendations in these areas, but we know that there has been little progress in implementing them, especially when it comes to providing palliative care and proper pain control and sedation techniques.

The committee called for governments to make palliative care a top priority in the restructuring of the health care system. In fact, the opposite seems to have happened. Due to health care cuts of recent years in many provinces, palliative care seems to have been a victim of disproportionate cutting and only four provinces have palliative care as a core part of their medical system.

Training aspects of palliative care need to be increased. Yet we note that the majority of medical schools in Canada still do not offer a certificate in palliative medicine created by the Royal College of Physicians and Surgeons and the College of Family Physicians of Canada, again primarily due to lack of funding.

The committee called for an integrated approach to palliative care. Yet, the evidence is that outside of a few urban centres, there is little coordination between palliative care centres in other parts of the health care system; and, perhaps more curiously, there has been very little progress in the area of home care, which is

avis, il y avait bien quelques lacunes dans le rapport de 1995, mais il contenait beaucoup d'excellentes recommandations dans le domaine des soins en fin de vie, et il s'agit d'un document marquant, fondé sur d'excellentes recherches.

Il convient maintenant de faire un suivi du rapport et de voir comment les gouvernements et d'autres ont réagi à ses recommandations unanimes. À notre avis, toutefois, le rapport devrait porter sur les recommandations unanimes relatives aux soins palliatifs plutôt que sur les changements législatifs controversés se rapportant plutôt à l'euthanasie et au suicide assisté. Comment se fait-il que dans les discussions sur la fin de la vie, c'est la charrette de l'euthanasie et du suicide assisté qui est mise devant les boeufs des soins palliatifs? Ou alors, comment se fait-il que tout le monde connaît le Dr Jack Kevorkian, alors que Mme Cicely Saunders, qui a fondé le mouvement moderne des soins palliatifs hospitaliers, est presque inconnue en dehors des milieux professionnels? Surtout quand on pense que la plupart d'entre nous, à la fin de leur vie, préféreraient être soignés par le Dr Saunders ou le Dr Ayoub, plutôt que par le Dr Kevorkian.

La Care-in-Dying Coalition est ravie que dans sa mise à jour le Sénat ait décidé de se concentrer sur les recommandations unanimes du rapport «De la vie et de la mort», dont bon nombre portaient sur les soins palliatifs, plutôt que de rouvrir le débat controversé sur l'euthanasie et le suicide assisté. Nous espérons qu'en préparant son rapport le comité maintiendra cet équilibre et consacrera davantage de son attention aux soins palliatifs qu'à une modification possible du Code criminel.

Le rapport «De la vie et de la mort» présentait des recommandations unanimes dans divers domaines importants: les soins palliatifs, le soulagement de la douleur et la sédation, le maintien et le retrait des traitements de survie et les directives préalables. La coalition appuie la grande majorité des recommandations du rapport sur ces questions, mais nous savons qu'on a fait peu de progrès dans leur mise en oeuvre, surtout pour ce qui est d'offrir des soins palliatifs et de bonnes méthodes de soulagement de la douleur et de sédation.

Le comité a demandé que les gouvernements fassent des soins palliatifs une priorité dans la restructuration des soins de santé. Il semble qu'en fait le contraire se soit produit. À cause des compressions budgétaires des dernières années, dans bien des provinces, les soins palliatifs ont été la victime de compressions disproportionnées, et seulement quatre provinces ont fait des soins palliatifs une partie essentielle de leur système de soins de santé.

Il faut augmenter la formation en soins palliatifs. Pourtant, nous constatons que la majorité des facultés de médecine au Canada n'offrent toujours pas le certificat en médecine palliative créé par le Collège royal des médecins et chirurgiens et par le Collège des omnipraticiens du Canada, encore une fois surtout faute d'argent.

Le comité a demandé qu'on adopte une démarche intégrée dans le domaine des soins de santé. Pourtant, en dehors de quelques centres urbains, il y a peu de coordination entre les centres de soins palliatifs des autres secteurs du système de soins de santé; et ce qui est plus étonnant, c'est qu'il y a eu très peu de progrès dans



essential for patients who want to be able to die in their own homes, surrounded by family.

The committee recommended that research into palliative care, especially pain control and symptom control, be expanded and improved. Again, the response has been underwhelming. The major funding bodies, such as the Medical Research Council and the National Cancer Institute of Canada, have provided only a tiny fraction of funding for palliative care research, and the new Canadian Institutes of Health Research have no programs in the area of end-of-life or palliative care.

Only in one area, the creation of national standards, does there seem to have been significant progress. Here the credit must go to the professional bodies, such as the Canadian Palliative Care Association, that have worked to develop the standards with little support from Health Canada or other departments of health.

This overall lack of progress in the area of palliative care is unacceptable and, we believe, contributes to a dangerous false dichotomy in this debate, where many people feel that assisted suicide or euthanasia is the only alternative to dying a painful, miserable death.

In the areas of pain control, sedation, and the withholding and withdrawal of life-sustaining treatment, the "Of Life and Death" report recommended that the Criminal Code of Canada be changed to clarify the legitimacy of providing pain relief, even where it may have an unintended effect of hastening death, and the circumstances under which treatment may be legitimately withheld or withdrawn. We acknowledge that there may be ambiguities in the existing Criminal Code that could use clarification, and so the coalition supports the intent of efforts such as Bill S-2 to clarify the withholding and withdrawal of treatment in certain circumstances and the proper use of medication to alleviate pain and to clarify how that is distinct from euthanasia or assisted suicide. However, we have serious concerns about the wording of the current Bill S-2, which we feel in certain circumstances may be interpreted as permitting euthanasia.

On another legal recommendation of the Senate report, the committee unanimously recommended that the Criminal Code be amended to provide for less severe penalty in cases where there is the essential element of compassion or mercy. The Care-in-Dying Coalition opposed and continues to oppose that recommendation of the Senate. While there may be valid reasons for reviewing mandatory sentencing provisions, it is extremely important to ensure that the changes apply to all cases of second degree murder and not only to cases where the motive is alleged to be compassionate, similar to what Mr. Scher said in his presentation earlier.

On January 30, 1998, in light of the debate over the *Latimer* case, the Care-in-Dying Coalition sent a letter to the Honourable Anne McLellan, urging that the law not be changed in this

le domaine des soins à domicile, qui sont essentiels pour les patients qui veulent mourir chez eux, entourés de leur famille.

Le comité recommande une augmentation et une amélioration des recherches en soins palliatifs, surtout dans le domaine du soulagement de la douleur et du contrôle des symptômes. Dans ces cas-là aussi, la réaction a été décevante. Les principaux organismes subventionnaires, soit le Conseil de recherches médicales et l'Institut national du cancer du Canada ne fournissent qu'une fraction infime du financement de la recherche en soins palliatifs, et les nouveaux Instituts canadiens de recherche en santé n'ont aucun programme dans le domaine des soins en fin de vie ou des soins palliatifs.

Il ne semble y avoir eu de progrès importants que dans un seul domaine, celui de la création de normes nationales. Tout le mérite en revient aux organismes professionnels, comme l'Association canadienne des soins palliatifs, qui ont travaillé à l'élaboration de normes, avec bien peu d'appui de Santé Canada ou d'autres ministères de la Santé.

Cette inertie dans le domaine des soins palliatifs est inacceptable, et nous estimons qu'elle contribue à une fausse et dangereuse dichotomie dans ce débat, qui fait en sorte qu'aux yeux de bien des gens le suicide assisté et l'euthanasie sont la seule autre option, si on ne veut pas mourir dans la douleur et sans dignité.

Dans le domaine du soulagement de la douleur, de la sédation et de l'abstention ou de l'interruption de traitements de survie, le rapport «De la vie et de la mort» recommandait que le Code criminel du Canada soit modifié de manière à établir la légitimité du soulagement de la douleur, même s'il peut avoir pour effet secondaire de précipiter la mort, et décrivait les circonstances dans lesquelles on peut s'abstenir de donner un traitement ou l'interrompre, légitimement. Nous reconnaissons que le Code criminel peut comporter des ambiguïtés qu'il faudrait clarifier et, par conséquent, nous appuyons les intentions à l'origine d'initiatives comme le projet de loi S-2, destiné à clarifier les circonstances de l'abstention ou de l'interruption d'un traitement, l'emploi approprié de médicaments destinés à soulager la douleur, et à distinguer ces démarches de l'euthanasie et du suicide assisté. Nous avons toutefois de graves préoccupations au sujet du libellé du projet de loi S-2, qui dans certaines circonstances, à notre avis, pourrait être interprété comme permettant l'euthanasie.

Au sujet d'une autre recommandation législative du rapport du Sénat, le comité a recommandé à l'unanimité que le Code criminel soit modifié pour alléger les peines dans les cas où peuvent être invoqués l'élément essentiel de compassion ou de pitié. La coalition s'y est opposée et continue de s'opposer à cette recommandation du Sénat. Il peut y avoir de bonnes raisons de revoir les dispositions obligatoires relatives à la détermination de la peine, mais il est extrêmement important de s'assurer que les changements s'appliquent à tous les cas de meurtre au second degré, et non pas seulement aux cas où on allègue un motif de compassion, comme le disait M. Scher dans son exposé.

Le 30 janvier 1998, à la lumière du débat entourant l'affaire *Latimer*, notre coalition a adressé une lettre à l'honorable Anne McLellan, l'exhortant à ne pas modifier la loi à ce sujet, et sept

respect, and seven members of the Care-in-Dying Coalition are currently intervenors before the *Latimer* sentence in the appeal in the Supreme Court of Canada.

While the coalition does have concerns about some of the legal issues raised by the report "Of Life and Death," and we are addressing those concerns in fora such as the Bill S-2 debate and the *Latimer* appeal, we say that our greater concern by far is that the debate over these contentious, divisive legal issues should not overshadow the imperative for action in the area of palliative care.

We think that the relevant recommendations to this committee of Dr. Chochinov of the Department of Psychiatry at the University of Manitoba were excellent and, with slight modifications, we would like to reiterate them as our own.

The Senate should support designated funding through the Medical Research Council, the Canadian Institutes for Health Research or other bodies to support palliative care training, service delivery and end-of-life research. All medical training facilities and licensing agencies should be required to provide training and assessment in the area of end-of-life care.

All health care facilities, including hospitals and long-term care facilities, should be required to demonstrate appropriate standards in end-of-life care. Health Canada should be held accountable for an annual report on the status of and progress of end-of-life care on a national basis.

We particularly like the recommendation that the name of the report should be "The Senate Report on End-of-Life Care in Canada." We think that that puts the emphasis where it should be. It would prevent the media from distorting this debate. Rather than focusing on euthanasia and assisted suicide, it should focus attention on the treatment of dying patients.

We also think that many of the more detailed recommendations of the Catholic Health Association of Canada — one of our member organizations who will appear here tomorrow — are excellent and complement some of those basic recommendations.

We believe that there is a significant crisis in the lack of access to palliative care in this country. It is that crisis, along with media sensationalism, that is fuelling calls for euthanasia and assisted suicide. We oppose euthanasia and assisted suicide as incompatible with human dignity and respect for human life. We are concerned to affirm the worth of the human life of the most vulnerable members of our society, such as the sick, the disabled and the elderly, and to ensure that there are effective advocates for the rights of those who cannot speak for themselves. We call for the Senate to deal with the problem of end-of-life care at its root by coming forward with a strong report urging that their excellent, unanimous recommendations in the areas of palliative care and pain control be acted upon by governments as an urgent priority.

membres de la Care-in-Dying Coalition sont des intervenants dans l'affaire *Latimer*, faisant l'objet d'un appel devant la Cour suprême du Canada.

Alors que la coalition a des préoccupations au sujet de certaines questions juridiques découlant du rapport «De la vie et de la mort», dont nous parlons dans le débat sur le projet de loi S-2 et dans le cadre de l'appel dans l'affaire *Latimer*, nous devons dire que ce qui nous préoccupe le plus, c'est que ce débat sur ces questions juridiques controversées puisse éclipser la nécessité d'agir dans le domaine des soins palliatifs.

Nous pensons que les recommandations pertinentes présentées à ce comité par le Dr Chochinov, du Département de psychiatrie de l'Université du Manitoba, étaient excellentes, et, avec de légères modifications, nous voudrions les présenter comme nôtres.

Le Sénat doit donner son appui à un financement réservé, par l'intermédiaire du Conseil de recherches médicales, des Instituts canadiens de recherche en santé et d'autres organismes, dans le but d'encourager la formation en matière de soins palliatifs, et la recherche sur les soins palliatifs et les soins en fin de vie. Tous les établissements d'enseignement de la médecine et les organismes d'accréditation devraient fournir la formation et l'évaluation dans la discipline des soins en fin de vie.

Tous les établissements de soins de santé, y compris les établissements d'hébergement et de soins de longue durée, devraient prouver leur conformité aux normes relatives aux soins en fin de vie. Santé Canada devrait être tenu de produire un rapport annuel sur l'état et l'avancement des soins en fin de vie, à l'échelle nationale.

La recommandation visant à renommer le rapport «Le Rapport du Sénat sur les soins en fin de vie au Canada» nous plaît particulièrement. Nous pensons qu'on insiste alors sur ce qu'il faut. On éviterait que les médias ne détournent le débat. Plutôt que de se concentrer sur l'euthanasie et le suicide assisté, on devrait se concentrer sur le traitement des mourants.

Nous pensons aussi que nombre des recommandations détaillées de l'Association catholique canadienne de la santé — une de nos organisations membres qui comparaitra ici demain — sont excellentes et complètent certaines de nos recommandations fondamentales.

Nous pensons que le manque d'accès aux soins palliatifs au Canada est une crise grave. C'est cette crise, de même que le sensationnalisme des médias, qui nourrit la demande pour ce qui est de l'euthanasie et du suicide assisté. Nous nous opposons à l'euthanasie et au suicide assisté, qui sont incompatibles avec la dignité humaine et le respect pour la vie humaine. Nous tenons à affirmer la valeur de la vie humaine des membres les plus vulnérables de notre société, comme les malades, les handicapés et les personnes âgées, et nous voulons nous assurer qu'il y ait des défenseurs efficaces des droits de ceux qui ne peuvent parler pour eux-mêmes. Nous demandons au Sénat de s'attaquer au cœur du problème des soins en fin de vie en présentant un rapport solide, en exigeant que ses excellentes recommandations unanimes dans le domaine des soins palliatifs et du soulagement de la douleur soient mises en oeuvre par les gouvernements, de façon urgente et prioritaire.



With that I should like to turn the podium over to Dr. Ayoub.

[Translation]

**Dr. Joseph Ayoub, Oncologist, Institut du cancer de Montréal:** My presentation will focus on the progress and shortcomings of palliative care in Canada.

Over the past few years, and further to the recommendation made by the Special Senate Committee on Euthanasia and Assisted Suicide, and by governments, to give priority to palliative care programs in restructuring the health system, we are witnessing the growth of institutional and non-institutional palliative care units throughout Canada.

Some hospital centres have, however, adopted a model which is not based on any geographic unit and which focusses more on consultative services provided by an expanded interdisciplinary team. However, the objective remains the same: to ensure that people, as they approach the end of their lives, are surrounded by human warmth and kindness while being given competent medical care to relieve physical suffering and any other major symptoms associated with their primary disease. The current challenge lies in establishing an optimal continuum of care and services to enable us to take the best comprehensive approach with the dying.

The Senate Special Committee had, in fact, recommended the adoption of an integrated palliative care approach. This has yet to be implemented. As a result, the coordination of care between hospital centres and local community service centres is not what it should be. Outpatient palliative care services are still in the process of being developed. In addition, home care resources for those individuals who wish to die at home are often inadequate. For example, respite care for informal caregivers is not satisfactory.

At any rate, access to the various services varies from one place to the other, creating regional disparities. As a result of these shortcomings, emergency services are often overtaxed and, consequently, many people spend their final days in the short-term-care ward or in the extended-care ward. In order to rectify the problem, we have made several suggestions, particularly with respect to the establishment of palliative care day centres and optimal home care for patients who are losing their autonomy.

As for the medical research and training activities advocated by the Senate Special Committee, these are the responsibility of the supra-regional and university units. For example, the Quebec cancer program stipulates the following supra-regional criteria: the participation in research activities, the responsibility for teaching so as to be at the leading edge of clinical therapeutic discoveries, and the obligation to make its expertise readily available to regional or local practitioners called upon to provide services to the dying.

Canadian universities have acknowledged that there must be an improvement in professional health training as regards all aspects of palliative care. Thus, for example, since July 1999 the University of Montreal has been requiring its family medicine

Sur ce, je donne la parole au Dr Ayoub.

[Français]

**Dr. Joseph Ayoub, oncologue, Institut du cancer de Montréal:** Je concentrerai ma présentation sur les progrès et les lacunes dans l'implantation des soins palliatifs au Canada.

Au cours des dernières années, et suite à la recommandation du comité spécial du Sénat sur l'euthanasie et l'aide au suicide et des gouvernements d'accorder une grande priorité aux programmes de soins palliatifs dans la restructuration du système de santé, nous assistons à l'essor des unités de soins palliatifs intra et extrahospitalières à travers tout le Canada.

Certains centres hospitaliers ont par contre adopté un modèle sans aucune unité géographique et axé plutôt sur des services de consultation auprès d'une équipe interdisciplinaire élargie. Cependant, l'objectif demeure d'entourer les personnes en fin de vie d'une chaleur humaine et surnaturelle, en plus de leur octroyer des soins médicaux compétents pour soulager la souffrance physique et autres symptômes importants reliés à leur maladie de base. Le défi actuel réside dans l'établissement d'un continuum optimal de soins et de services destinés à une meilleure approche globale des personnes en fin de vie.

Le comité spécial du Sénat avait en effet recommandé l'adoption d'une approche intégrée des soins palliatifs. Ceci reste encore à être mis en pratique. Ainsi, il existe une coordination sous-optimale des interventions entre les centres hospitaliers et les centre locaux de services communautaires. Quant aux services ambulatoires en soins palliatifs, ils sont uniquement en voie d'être développés. De plus, les ressources allouées pour le maintien à domicile des personnes désirant mourir chez elles sont souvent insuffisantes. On note donc une faiblesse des services de répit aux aidants naturels.

De toute façon, l'accès aux différents services est inégal d'un endroit à l'autre, créant ainsi des disparités régionales. Ces lacunes produisent souvent un encombrement du service des urgences et, conséquemment, l'hospitalisation en lit de courte durée ou en soins prolongés d'un bon nombre de personnes en fin de vie. C'est dans ce contexte que plusieurs correctifs sont présentement proposés, notamment dans la création de centres de jour en soins palliatifs et le maintien à domicile optimal pour les patients en perte d'autonomie.

Quant aux activités de recherche et de formation médicale prônées par le comité spécial du Sénat, elles sont prises en charge par les unités suprarégionales et universitaires. Le programme québécois de lutte contre le cancer, par exemple, précise les critères suprarégionaux suivants: la participation à des activités de recherche, la responsabilité de l'enseignement permettant d'être à la fine pointe des découvertes thérapeutiques cliniques et l'obligation de rendre son expertise facilement accessible aux intervenants régionaux ou locaux appelés à donner des soins de fin de vie.

Les universités canadiennes ont pris acte de la nécessité d'améliorer la formation des professionnels de la santé dans tous les aspects des soins palliatifs. C'est ainsi, par exemple, que l'Université de Montréal, dès juillet 1999, oblige les résidents en



residents to take four week's training in a palliative care unit. Moreover, the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada as of July 1999 were delivering certificates of competence in palliative medicine for residents taking one year's training in an accredited centre.

Finally, palliative care training courses and conferences are to be found everywhere in Canada thus allowing the majority of health professionals to acquire the knowledge necessary to take care of those patients.

I would like to conclude by mentioning that the palliative care experience has led us to be aware of one fact: only love allows one to honour the dignity of human life. The person who is going to die does not only need our medical proficiency, that person also wants someone present, affection, an outstretched hand. If we can share our hope with them, serenity sets in and death is no longer feared. For that to occur, the health professionals and family members must be ready to make the effort and spend the time necessary to accompany the person to the end of life's journey. If you can manage that, then the question of euthanasia becomes futile.

As Ms Thérèse Vanier mentioned, when the attending physicians recognize there is nothing more to be done in the way of active treatment, then everything remains to be done.

[English]

**The Chairman:** Thank you, Mr. Cameron, before I move on to the next witness, you know that I am the person who initiated Bill S-2.

**Mr. Cameron:** Yes, I do.

**The Chairman:** I also want you to know, very sincerely, in front of the television cameras, that I do not want Bill S-2 to be anything but the very best it can be. I would welcome any amendments that come forward.

**Mr. Cameron:** We have a presentation on Bill S-2, which I will certainly circulate to all committee members.

**The Chairman:** Thank you very much.

We will hear next from Dr. John Mahony. Thank you for coming on such short notice.

**Mr. James Mahony, Alberta Life Foundation:** Honourable senators, I want to say that I am very impressed by the presentations today. I say to my colleagues that they are a hard act to follow.

I will concentrate on a question that Peter Ryan asked: Can a finding of compassionate homicide result from an omission? That is an issue with which I also tend to concur. In my view, the report was perhaps a bit short in exploring that particular issue. In fact, I would characterize it by saying that, in my view, that will be the battleground. There is an immense scope for abuse there. It has been explained to me a number of times that this area is not black and white, that there is a lot of grey, and I appreciate that.

médecine familiale à suivre un stage de quatre semaines dans une unité de soins palliatifs. De plus, le Collège des médecins de famille du Canada ainsi que le Collège Royal des médecins et chirurgiens du Canada délivrent dès juillet 1999 des certificats de compétence en médecine palliative aux résidents qui suivent un an de formation dans un centre accrédité.

Finalement, les cours de formation et les congrès en soins palliatifs abondent un peu partout au Canada, permettant ainsi au plus grand nombre de professionnels de la santé d'acquérir les connaissances nécessaires pour prendre soin de ces patients.

Je voudrais conclure en mentionnant que l'expérience des soins palliatifs nous a fait prendre conscience d'un fait: seul l'amour permet d'honorer la dignité de la vie humaine. La personne qui va mourir n'a pas uniquement besoin de notre compétence médicale, elle désire aussi une présence, de l'affection, une main tendue. Si nous sommes capables de lui transmettre l'espérance qui nous anime, une sérénité s'installe en elle et elle n'a plus peur de la mort. Pour cela, il faut que les professionnels de la santé et les membres de la famille soient prêts à faire l'effort et à mettre le temps nécessaire pour l'accompagnement de la personne en fin de vie. Si on y arrive, la question de l'euthanasie devient futile.

Tel que l'a mentionné Mme Thérèse Vanier, c'est au moment où les médecins traitants reconnaissent qu'il n'y a rien de plus à faire activement que tout reste encore à faire.

[Traduction]

**La présidente:** Merci, Monsieur Cameron, avant de passer au témoin suivant, j'aimerais préciser que c'est moi qui ai déposé le projet de loi S-2.

**M. Cameron:** Oui, je le sais.

**La présidente:** Je voudrais aussi ajouter ceci pour le bénéfice de tous nos auditeurs: je ne demande pas que le projet de loi S-2 soit l'alpha et l'oméga, mais je voudrais qu'il soit aussi bon que possible, et c'est pourquoi j'accueillerai avec plaisir tout amendement qu'on pourra proposer.

**M. Cameron:** Nous avons préparé quelque chose sur le projet de loi S-2, et nous le ferons distribuer à tous les membres du comité.

**La présidente:** Merci beaucoup.

Nous accueillons maintenant M. John Mahony, qui se joint à nous malgré le bref préavis.

**M. James Mahony, Alberta Life Foundation:** Mesdames et messieurs, d'entrée de jeu j'avoue que je suis très impressionné par la teneur des exposés d'aujourd'hui. J'essaierai de faire aussi bien que mes collègues de la table ronde.

Je vais m'attarder sur la question posée par Peter Ryan: est-ce qu'un jugement d'homicide par compassion peut résulter d'une omission? C'est ce que j'ai tendance à croire. À mon avis, le rapport n'a peut-être pas exploré la question à fond. En fait, je dirais même que cette question deviendra le champs de bataille, car elle laisse la porte grande ouverte aux abus. On m'a expliqué à maintes reprises que dans ce domaine ce n'était ni tout blanc ni tout noir, mais surtout très gris. Je comprends.

I will talk today in reference to one particular recommendation the committee made in the report — the unanimous recommendation that the Canadian provinces that had not passed advance directive legislation do so. In relating this to the issue of compassionate homicide, the scope for passive euthanasia with respect to advance directives is great. I will go into that a little more.

The medical community, the health care community, and the people generally in hospitals and nursing homes that I have talked to approved the use of advance directives — personal directives as they are called in Alberta — I would say close to 100 per cent. I represent the Alberta Life Foundation and my own opinion, which is perhaps not a large segment of the population, but I do not hesitate to say that my position is considered heresy in the medical community. I have spoken to many doctors in Western Canada, particularly in Alberta, and I found very few who agree with my position. I believe that advance medical directives, whether they are called personal directives or whatever term is used, are a mistake. I believe that ultimately the result in many cases will lead to the practice of passive euthanasia.

By passive euthanasia, I am referring to of course what Mr. Ryan spoke of, which is essentially the dehydration of patients and their ultimate death. The whole issue of nutrition and hydration and characterizing nutrition and hydration as medical treatment is problematic, again for the reasons that Mr. Ryan stated. We are talking about food and water, to use simple terms. Once you characterize a necessity of life as medical treatment, it becomes a relatively straightforward matter to withhold that necessity on the basis that it is medical treatment. That is particularly the case where there has been an advance directive signed by the individual.

I am not sure that the act that was passed in Alberta was in direct response to the committee's recommendation. The Personal Directives Act is in many ways similar although not identical to legislation passed elsewhere in Canada. I do not propose to go through all the statutes in all the provinces. At least half if not more provinces in Canada have passed directive legislation. In Ontario, I believe it is called the Substitute Decisions Act. In any case, I have spent a few years studying this material and studying in particular advance directives and the legislation that supports them. The more I study it, the more my concerns grow. Before the committee, this point might not be relevant, but it seems to me that particularly where the committee appears to believe that advance directives and their use would somehow, if not solve the problem, at least contribute to a solution or become part of the solution, I have concerns.

From my perspective, the reason d'être of advance directives is the withdrawal of care, particularly in circumstances where the result will be the patient's death. One of the terms that has been used to describe some of the advance directive statutes in Canada and the U.S., and again I have not heard it before this committee today, is "death by choice" legislation. Most of you may have heard that term in reference to statutes that would legalize or

Je me reporterai aujourd'hui à une des recommandations du rapport, soit la recommandation unanime du comité disant que les provinces canadiennes qui n'ont pas encore adopté de loi sur les directives préalables le fassent. Dans le cadre de la question de l'homicide par compassion, le lien entre l'euthanasie passive et les directives préalables est énorme. Je vais creuser le sujet un peu plus.

Le corps médical, le milieu des soins de santé et ceux qui oeuvrent dans les hôpitaux et dans les centres de soins à qui j'ai parlé approuvent de façon générale le recours aux directives préalables — que l'on appelle directives personnelles en Alberta — et ce, à hauteur de presque 100 p. 100. Je suis ici comme porte-parole de l'Alberta Life Foundation et aussi en mon nom personnel, ce qui ne représente pas nécessairement une grande partie de la population, mais je n'hésite pas à dire que mon point de vue est considéré comme une hérésie dans le milieu médical. J'ai parlé à beaucoup de médecins de l'Ouest du Canada, et surtout en Alberta, et j'ai constaté que très peu d'entre eux sont d'accord avec moi. Je suis d'avis que les directives préalables médicales, appelées aussi ailleurs les directives personnelles, sont une erreur, car elles peuvent mener en bout de piste dans bien des cas à la pratique de l'euthanasie passive.

Par l'euthanasie passive, j'entends ce dont parlait M. Ryan, soit essentiellement la déshydratation des patients, ce qui entraîne leur mort. Parler de la nutrition et de l'hydratation comme d'un traitement médical pose problème, pour les raisons que M. Ryan a établies. Pour parler franc, il s'agit après tout de nourriture et d'eau. Dès lors que l'on considère les choses nécessaires à la vie comme étant un traitement médical, il devient par conséquent relativement simple de retirer cette nécessité en prétendant qu'il s'agit d'un traitement médical. C'est particulièrement le cas là où le patient a déjà signé des directives préalables.

Je ne sais pas si la loi que l'Alberta a adoptée représentait une réponse directe à la recommandation du comité. La loi «Personal Directives Act» est à bien des égards semblable, quoique non identique, aux lois adoptées ailleurs au Canada. Je ne me propose pas de les passer toutes au peigne fin. Au moins la moitié, voire plus, des provinces canadiennes ont adopté des lois sur les directives préalables. En Ontario, je crois que cette loi s'appelle la Loi sur la prise de décisions au nom d'autrui. Quoi qu'il en soit, j'ai étudié pendant quelques années la question, et plus particulièrement les directives préalables et les lois qui les permettent. Or, plus j'étudie la question, et plus je suis préoccupé. Cela ne semble peut-être pas pertinent pour votre comité, mais la question me préoccupe particulièrement du fait que le comité semble croire que les directives préalables et le recours à ces directives pourraient éventuellement contribuer à résoudre le problème partiellement ou complètement.

De mon point de vue, la raison d'être des directives préalables, c'est le retrait des soins, particulièrement dans les cas où il en résulterait la mort du patient. L'une des expressions que l'on a utilisées pour décrire certaines des lois sur les directives préalables au Canada et aux États-Unis — mais on ne l'a pas encore mentionnée aujourd'hui devant vous — c'est la loi sur la mort par choix. Vous avez certainement, la plupart d'entre vous,



decriminalize euthanasia or assisted suicide. I agree with that, but in my view it would also apply to the Personal Directives Act in Alberta.

I said that the reasoning behind the act was the withdrawal of care, particularly in circumstances where death will be the result. I also believe that professional liability, in other words, protection from lawsuits, is a concern, particularly on the part of health care associations. Some of the medical associations have made representations in support of this legislation. I do not think I am being too cynical about this. Very few physicians will come forward and endorse or support the legislation on those grounds, but it seems to me that that is a strong factor.

In Alberta, to digress again for a moment, section 28 of the Personal Directives Act protects health care providers. I think the term is service providers, which of course includes not only physicians but other health care professionals like nurses. In my view, and in the view of some of the people with whom I have talked, professional liability concerns are a major part of these sorts of statutes being supported in Canada and the U.S. Actually, the first person who mentioned that to me was a doctor who practises in Alberta today. He said that in the U.S., the motivation is liability protection for doctors. I asked him if it was any different in Canada, and his response was that we are a little more altruistic in Canada.

With respect to physicians in Canada, I am not challenging or attacking the motivation of many of the people who support these initiatives. I know that many doctors and nurses support this kind of legislation because they believe it is essentially a kind of patient welfare legislation, but I am not too cynical by saying that many of them are motivated by professional liability concerns.

Beyond that, I would have to say that another motive is what I referred to earlier when I mentioned the death-by-choice legislation. In some cases I believe there is a death wish by patients. In that respect, a report was published in 1993 by the Society for the Protection of Unborn Children in Great Britain. They described advance directives at length. One of the terms they mentioned was "advance refusal". In other words, an advance directive in Britain is often referred to as an advance refusal of treatment, which to me puts the lie to the suggestion that directives are nothing more than a way of making choices in health care. In my view, an advance directive is in many cases a way to eliminate health care.

Someone referred briefly to the creation of a two-tier medical system. At the rate that statutes are being passed in Canada and at the rate that the medical community is embracing the use of

entendu cette expression lorsque l'on parle des lois qui servent à légaliser ou à décriminaliser l'euthanasie ou l'aide au suicide. Je suis d'accord, mais je crois que cette expression pourrait également s'appliquer à la loi sur les directives personnelles de l'Alberta.

J'ai dit que la raison d'être de la loi, c'était le retrait des soins, particulièrement dans les cas où la mort en résulterait. Je crois également que la responsabilité professionnelle, c'est-à-dire la protection contre des poursuites, préoccupe particulièrement les associations de soins de santé. Certaines des associations médicales ont dit officiellement appuyer cette loi. Ce n'est pas faire preuve de trop de cynisme que d'en parler. Très peu de médecins se prononceront officiellement ou appuieront la loi pour cette raison, mais je crois que c'est un des éléments clés qui expliquent leur appui.

Laissez-moi digresser encore un peu: en Alberta, l'article 28 de la loi sur les directives personnelles protège le personnel soignant. Je crois que l'on parle dans la loi de fournisseurs de services médicaux, ce qui inclut bien sûr non seulement les médecins, mais aussi les autres professionnels de la santé, comme les infirmières. À mon avis, et de l'avis de certains à qui j'ai parlé, les préoccupations quant à la responsabilité professionnelle sont un des aspects importants de ces mesures législatives qui trouvent leur appui dans la population canadienne ou américaine. D'ailleurs, la première personne qui m'en ait parlé, c'était un médecin qui pratique aujourd'hui en Alberta. Il m'a expliqué qu'aux États-Unis ce qui motivait l'appui à la loi, c'était la protection qu'on offrait aux médecins contre les poursuites. Lorsque je lui ai demandé si la situation était différente au Canada, il m'a répondu qu'ici nous faisons preuve d'un peu plus d'altruisme.

En ce qui concerne les médecins canadiens, je ne remets pas en question les motifs de ceux qui appuient ces initiatives. Je sais que beaucoup de médecins et d'infirmières sont d'accord avec ce type de loi, parce qu'ils croient que cela équivaut à protéger le bien-être du patient, mais je répète que ce n'est pas faire preuve d'un trop grand cynisme que d'affirmer que beaucoup d'entre eux sont aussi motivés par des préoccupations concernant leurs responsabilités professionnelles.

En outre, il y a une autre chose qui les motive, et j'en ai parlé plus tôt en mentionnant la loi sur la mort par choix. Dans certains cas, je crois même que l'on peut parler de souhait de la mort de la part des patients. Un rapport a d'ailleurs été publié là-dessus en 1993 par la société pour la protection des enfants à naître de la Grande-Bretagne. Dans ce rapport, on décrivait longuement les directives préalables. On parlait même notamment de «refus préalable». Autrement dit, on parle souvent en Grande-Bretagne d'une directive préalable comme étant un refus préalable d'être traité, ce qui, à mon avis, vient contredire l'affirmation selon laquelle les directives ne sont rien de plus qu'un choix de plus que l'on offre aux patients en matière de soins de santé. À mon avis, la directive préalable constitue très souvent une façon d'éliminer les soins de santé.

Quelqu'un a mentionné brièvement la création d'un régime médical à deux vitesses. Au rythme auquel on adopte les lois au Canada et auquel le milieu médical adhère aux directives



advance directives. I would suggest to you that the development of a two-tier medical system or health care system will be accelerated by the use of advance directives for the simple reason that there is no greater or more effective tool for managing health care costs than directives. Essentially, a directive is a document that says what a patient does not want — in other words, what forms of health care they do not want at a certain situation in life.

In Alberta we hear it more than we do in other provinces, but in hospitals today, costs seem to be becoming the major factor in determining policy and in the way decisions are made. I would refer you to the Patient Self-Determination Act in the U.S., which provides that, if a hospital admits a patient without giving him the option to sign an advance directive, it can potentially lose federal funding. Given the size of some U.S. hospitals and the magnitude of the budgets we are talking about, that is a very large stick to hold over the head of hospital administrators. Again, from my perspective, it is related to costs.

I do not suggest that all who support the use of advance directives are motivated by cost or by budgetary concerns. I am saying that the very real potential exists that these things, which, in many cases, were the result of people being sincerely concerned about patient welfare, ultimately will become cost-control tools. They will become another management tool in the budget in the hospital administrator's repertoire.

Further to what was said earlier about the two-tiered health care system, I have thought about these things fairly sincerely. I do not speak as a hospital administrator or a doctor. This is a debate that should not be monopolized by health care professionals. In Alberta, however, some of the seminars and conferences I have attended have been strongly dominated by health care professionals, to the point that some of us standing outside that circle wonder whether or not our input is of any value.

I believe it is healthy to hear from people outside the health care system. As a lawyer, if I were to suggest that only lawyers should regulate lawyers, I would be ridiculed. We do have law societies in Alberta, but we are pretty closely supervised by the general public and by governments. Any suggestion that only lawyers should be the ones who, if you like, keep watch over lawyers would be laughed out of the room.

In this respect, it is healthy to have some input from outside the health care system, particularly in cases where, as with Alberta's Personal Directives Act, the liability protection that is being gained is being gained expressly for health care professionals. That is not to say that there are not other parts of this statute that protect other individuals; there are, and I will come to them, but I suggest that this was passed to protect the health care

préalables, je pense que le développement d'un régime médical à deux vitesses ou d'un nouveau régime de soins de santé sera accéléré par le recours aux directives préalables, pour la simple raison que ces directives sont ni plus ni moins la meilleure façon et la façon la plus efficace de gérer les coûts en matière de soins de santé. Autrement dit, les directives ne sont ni plus ni moins qu'un document décrivant ce que le patient refuse, c'est-à-dire quelles formes de soins de santé il refuse de recevoir à un moment donné de sa vie.

En Alberta, il y a une chose dont on parle peut-être plus souvent que dans les autres provinces: dans les hôpitaux, les coûts semblent en voie de devenir le facteur principal dont on tient compte aujourd'hui avant de déterminer la politique à suivre et avant de prendre les décisions. Je vous renvoie à la loi américaine appelée «Patient Self-Determination Act» en vertu de laquelle si un hôpital admet un patient sans lui offrir à son arrivée la possibilité de signer une directive préalable, il peut éventuellement perdre ses fonds fédéraux. Étant donné la taille de certains des hôpitaux américains et l'ampleur des budgets dont on parle, c'est toute une épée de Damoclès que l'on maintient au-dessus de la tête des administrateurs des hôpitaux! À mon point de vue, c'est encore une fois lié aux coûts.

Je ne veux pas laisser entendre que tous ceux qui sont d'accord avec les directives préalables sont motivés uniquement par les coûts ou par leur budget. Tout ce que je dis, c'est qu'il ne faut pas nier la possibilité bien réelle que ces dispositions, qui, dans bien des cas, avaient été suggérées par des gens qui s'inquiétaient sincèrement du bien-être du patient, puissent en bout de piste se transformer en outils de contrôle des coûts. Cela pourrait devenir un outil de gestion budgétaire de plus dans l'arsenal des administrateurs d'hôpitaux.

Pour revenir sur ce que l'on a dit plus tôt au sujet d'un régime de santé à deux vitesses, je me suis posé la question de façon très sincère. Je ne suis pas ici à titre d'administrateur d'hôpital ou de médecin. D'ailleurs, le débat ne devrait pas être monopolisé par les professionnels de la santé. Toutefois, certains des colloques et conférences auxquels j'ai assisté en Alberta étaient fortement dominés par les professionnels de la santé, au point que certains d'entre nous de l'extérieur se demandaient si leur opinion avait quelque importance.

Il est sain d'écouter ceux qui sont à l'extérieur du système de soins de santé. Si, comme avocat, je devais affirmer que seuls les avocats doivent régir leurs confrères, je serais tourné en ridicule. Nous avons un ordre des avocats en Alberta, mais nous sommes tout de même surveillés de très près par la population et par les gouvernements. Toute suggestion disant que seuls des avocats devraient surveiller les actes de leurs confrères serait immédiatement tournée en dérision.

Dans le cas qui nous occupe, il est sain d'aller voir ce qu'en pensent ceux qui sont à l'extérieur du régime de santé, particulièrement dans les cas où, comme pour la loi albertaine sur les directives personnelles, la protection contre les poursuites n'est accordée expressément qu'aux professionnels de la santé. Cela ne veut pas dire que les autres dispositions de la loi ne protègent pas d'autres individus aussi; il existe d'autres dispositions de ce genre.

professionals who will be pulling the plug in many instances, albeit under the instructions of patients.

This act, and other personal directives or other advance directives acts that I have looked at are rife with conflicts of interests. As one simple example: a life insurance beneficiary who is also a health care agent appointed by the maker of a directive, is, under this act, guaranteed freedom from at least civil liability for pulling the plug. That is also the case for estate beneficiaries, for someone who is a beneficiary under a will. Any statute that says to a person, "You have the power and the authority to disconnect another individual from life support in a situation where the immediate result is going to be death, but you also will benefit from the will or from a life insurance policy," causes an inherent conflict of interest. That is what I call it. It is certainly not something I have read about in the newspapers in Alberta. Those are two conflicts that are in here, but, in my view, it is rife with them.

If I can comment further about advance directives, one of the issues in health care today is informed consent. We are hearing about that a fair amount, mostly in the context of present health care decisions. In other words, if I am going in for surgery, I am informed of the potential risks, the potential benefits, and given the opportunity to make a decision. With a personal directive or an advance directive, a patient is asked to sign a form that gives, years or decades in advance, his health care agent, and the medical staff who act under that person's instructions, the instructions and consent to deliver medical treatment.

In any other situation, we would ask whether the consent that is being given is based on current information. In other words, if I am given an option for surgery for myself, how current is my information?

An advance directive essentially is a kind of blanket consent. It is a blank cheque for medical treatment and it is a blank cheque that will cover, in some cases, many, many years to come. A person who has given that consent might be informed, if it is a matter of an imminent illness, but in many cases the treatment that this person will receive will be years or decades after he has signed that form. Nevertheless, he has given the consent in the form.

My point is this: An advance directive is not real, current, consent. It is essentially a form of anticipated consent and it is really, as I said before, a form of blanket consent that is given many years in advance, in many cases well before the patient will have contracted any illness or condition.

et j'y viendrai, mais ce que je pense, c'est que ces dispositions ont été adoptées pour protéger les professionnels de la santé, qui seront ceux qui débrancheront les respirateurs la plupart du temps, même si c'est sur les instructions de leurs patients.

Cette loi-ci, tout comme les autres lois sur les directives personnelles ou préalables que j'ai examinées, ouvre grand la porte aux conflits d'intérêts. Prenons un exemple: un bénéficiaire d'assurance-vie, qui est également le mandataire nommé par le signataire d'une directive, est d'après la loi libre de toute poursuite au civil s'il débranche le respirateur. Il en va de même pour les légataires, c'est-à-dire ceux qui héritent en vertu d'un testament. Imaginez une loi qui dirait à une personne: «Vous avez le pouvoir et l'autorisation de débrancher un autre être humain de tout équipement de maintien en vie, avec comme résultat immédiat sa mort, mais il se trouve aussi que le testament vous nommera légataire, ou encore que vous allez hériter de son assurance-vie»; elle porterait en elle les germes d'un conflit d'intérêts. C'est ce que fait cette loi-ci. Les journaux n'en ont en tout cas pas parlé en Alberta. Je viens de vous parler de deux conflits que la loi entraîne, mais à mon avis il y en a beaucoup d'autres.

Pour continuer au sujet des directives préalables, il faut comprendre que l'un des aspects des soins de santé d'aujourd'hui, c'est le consentement en connaissance de cause. On en parle assez souvent, particulièrement lorsqu'il est question de décisions prises actuellement en matière de soins de santé. Autrement dit, si je dois subir une chirurgie, on m'informe des risques possibles, mais aussi des avantages que je pourrais en retirer, après quoi je prends ma décision. Dans le cas des directives personnelles ou préalables, on demande au patient de signer un formulaire qui donne des années, voire des décennies, à l'avance à l'agent qui s'occupera de lui assurer des soins de santé, ainsi qu'au personnel médical qui agira sur les instructions de cet agent, les instructions et le consentement voulus en prévision de traitements médicaux.

Dans toute autre situation, nous nous demanderions si le consentement accordé se base sur de l'information d'actualité. Autrement dit, si on me propose aujourd'hui de subir une chirurgie, l'information qu'on me donne est-elle d'actualité?

Or, une directive préalable constitue ni plus ni moins qu'un consentement général. C'est un chèque en blanc destiné au traitement médical, qui, dans certains cas, ne s'appliquera que dans de nombreuses années. Si la personne qui donne son consentement souffre d'une maladie pour laquelle elle devrait recevoir des traitements imminents, il est probable que les renseignements qu'elle reçoit seront d'actualité; mais dans bien des circonstances il faudra des années avant que l'on ne vienne à traiter la personne qui a signé le formulaire. Toutefois, elle aura déjà donné son consentement.

Ce que j'essaie de vous faire comprendre, c'est que la directive préalable ne constitue pas véritablement un consentement réel ou contemporain à l'intervention. C'est ni plus ni moins qu'un formulaire de consentement anticipé et, je le répète, un consentement général accordé de nombreuses années à l'avance, souvent longtemps avant que le patient n'ait contracté une maladie ou subi un accident.



Again, that is simply one of many different reservations I have about the documents. If I had to identify one reservation as the most important, it would be that advance directive statutes are built around choosing death, around facilitating death.

Peter Ryan talked about whether or not an omission can constitute compassionate homicide. I would suggest that in many cases that is what these documents will be for. In the British report I mentioned, published in 1993, the term used was "suicidal ideation," and it questions what there is to stop someone who is suicidal from simply making out one of these documents and letting nature take its course. In many cases, there will be suicidal intent here.

My concern is that in Canada there seems to be a waning respect for the value of human life. I appreciate that some people believe that personal autonomy and choice trump all other factors; that personal autonomy is either the only thing or the most important thing that matters. However, there are other factors involved here than personal autonomy and choice. In cases where people are making decisions that may lead to their own death, surely there must be some scope there to balance the equation with respect for human life.

If I were persuaded that personal autonomy or choice were not the prevalent factors here already, having read the report, I am not sure I would mention this, but my reading of the report suggests to me that there is respect for human life, but that there are other factors that are being brought into the equation. Personal autonomy and choice are not the most important factors here and they should not be allowed to dictate the debate.

**The Chairman:** Thank you. Before we go to questions, Senator Corbin has asked to be allowed to raise a point of order.

**Senator Corbin:** Yes. The recommendation in the report of June 6, 1995, is represented as a unanimous recommendation. However, I rose in the Senate on Wednesday, June 28, 1995, and I said:

[Translation]

... today, I want to dissociate myself from the opinion or unanimous recommendation to the effect that the Minister of Justice — and that was one of our recommendations, I acknowledge it — should consider instituting a definition of murder in the third degree, murder by compassion, in order to decrease the penalty.

I find that if there is "compassion" when murder is committed, a jury and a judge will know what to make of it. But going as far as saying we should set up a third category for murder to my mind is perhaps inviting certain individuals to make use of what, basically speaking, becomes a subsequent defence, in other words a motive to commit murder. I think this leads to a decrease in the respect that is owed to life.

Ce n'est là qu'une des nombreuses réserves que j'ai au sujet de ces documents. Si je devais en cibler une seule comme étant la plus importante, je dirais que les lois sur les directives préalables reviennent à permettre de choisir la mort et de la faciliter.

Peter Ryan s'est demandé si une omission pouvait être considérée comme un homicide par compassion. J'irais jusqu'à dire que dans bien des circonstances c'est ce à quoi serviront ces documents. Dans le rapport britannique que j'ai mentionné, qui a été publié en 1993, on parlait de «idéation suicidaire», et on se demandait ce qui pouvait empêcher un suicidaire de fabriquer simplement un de ces documents, puis de laisser la nature suivre son cours. Dans bien des cas, on pourrait parler d'intention suicidaire.

Ce qui me préoccupe, c'est qu'on semble respecter de moins en moins la vie humaine, ici au Canada. Je sais que, pour certains, l'autonomie et le choix personnels supplantent tous les autres facteurs et que l'autonomie personnelle est soit la seule chose dont il faut tenir compte, soit la plus importante. Toutefois, il y a d'autres facteurs qui entrent en jeu, outre l'autonomie et le choix personnels. Dans les cas où des gens prennent des décisions qui peuvent entraîner leur propre mort, il faudrait pouvoir mettre les choses en perspective et pondérer leur volonté et le respect de la vie.

Si, après avoir lu le rapport, j'étais persuadé que l'autonomie et le choix personnels n'étaient pas les facteurs dominants dans le cas qui nous occupe ici, je ne suis pas sûr que je mentionnerais ce qui suit; toutefois, la façon dont j'interprète le rapport me laisse croire que l'on respecte la vie humaine, mais qu'il y a également d'autres facteurs que l'on fait intervenir dans l'équation. Dans ce débat, l'autonomie et le choix personnels ne sont pas les facteurs les plus importants et ne devraient pas orienter le débat.

**La présidente:** Merci. Avant de passer aux questions, le sénateur Corbin a demandé à invoquer le Règlement.

**Le sénateur Corbin:** En effet. On présente la recommandation du rapport du 6 juin 1995 dont il est question aujourd'hui comme étant unanime. Toutefois, le mercredi 28 juin 1995 j'ai pris la parole au Sénat et j'ai dit ce qui suit:

[Français]

[...] je veux aujourd'hui me dissocier de l'opinion ou de la recommandation unanime à l'effet que le ministre de la Justice, et c'était une de nos recommandations, je le dis bien, devrait considérer d'établir un troisième degré de meurtre, le meurtre par compassion, de façon à réduire la peine.

Je trouve que s'il y a «compassion» dans la commission d'un meurtre, un jury et un juge sauront faire la part des choses. Mais de là à dire que nous devrions établir une troisième catégorie de meurtre, je pense que c'est peut-être inviter certains individus à se servir de ce qui est, au fond, une défense subséquente, comme d'un motif pour commettre un meurtre. Je pense que cela entraîne une dégradation du respect qui est dû à la vie.



I apologize to my colleagues, to the Chair and the Vice-Chair and other members of the committee; I should have stated this when we were examining the text. I was not here last week. I intended to come back to it. I was absent, so I missed the opportunity. First and foremost, I want to live at peace with my own conscience. That is why I am stating this today.

The majority recommendations in the report are also my recommendations in all respects, except for the matter I have just raised.

[English]

I have to live with the consequences, but I did make that statement in the Senate. I do not mind if there is continued reference to that recommendation as being the unanimous view of the committee. It was when the report was tabled. However, because of my absence, I did not contribute to the debate and the editing of that particular recommendation. I would not have supported it had I been present in committee. That is all I want to say.

**The Chairman:** Thank you, Senator Corbin. I was certainly in the chamber when you made that very passionate statement.

**Senator Beaudoin:** Do you agree generally with our lexicon? I listened carefully today to all your proposals. It is obvious that you are against the suggestion of third-degree murder. I took note of that, because in my opinion it is very important.

[Translation]

Dr. Ayoub, do you agree with our lexicon and, if not, why not? I have always said that if we define the terms at the outset of a discussion, then we gain hours, days and months in the discussion. We often realize, after all our discussions, that we were not using the same definitions.

You spoke brilliantly about palliative care. The members of the committee are certainly all on the same wavelength on this matter. If there is a point we all agree on, it has to be that one. You recommend the development of palliative care, but do you have any suggestions for us on that? In large part, this care falls under provincial jurisdiction. We'll be discussing it in our June report, but it might be good to have your views on that to be able to convey them to the provincial authorities.

**Mr. Ayoub:** What is important to note is that there is still no continuum in palliative care. There are good units in place, but there is no relationship between these units, local community service centres and home care. The lack of financial resources is to blame for that and it means that we cannot provide relief to the patients' families. If the resources were better, we could establish this continuity between the different end-of-life services.

Je m'excuse auprès de mes collègues, auprès de la présidente et de la vice-présidente et des autres membres du comité, j'aurais dû affirmer cela au cours de l'étude du texte. J'étais absent la dernière semaine. J'avais l'intention de revenir sur la question. J'étais absent, donc j'ai manqué l'occasion. Je veux, d'abord et avant tout, vivre en paix avec ma propre conscience. C'est pour cette raison qu'aujourd'hui, je fais cette affirmation.

Les recommandations de la majorité dans le rapport sont aussi mes recommandations sur tous les points, sauf sur celui dont je viens de parler.

[Traduction]

Je dois en accepter les conséquences, mais j'ai bel et bien déclaré cela au Sénat. Je comprends que l'on parle constamment d'une recommandation unanime de la part du comité, puisqu'il y avait unanimité au moment du dépôt du rapport. Toutefois, comme j'avais été absent, je n'avais pu prendre part au débat ni à l'élaboration de cette recommandation. Si j'avais été présent au comité, je ne l'aurais pas appuyée. Voilà ce que j'avais à dire.

**La présidente:** Merci, sénateur Corbin. J'étais été moi-même au Sénat lorsque vous avez apporté cette précision avec beaucoup de passion.

**Le sénateur Beaudoin:** De façon générale, êtes-vous d'accord avec les termes que nous avons choisis? J'ai écouté avec soin toutes vos propositions. Il saute aux yeux que vous n'acceptez pas la suggestion de créer la catégorie de meurtre au troisième degré. J'en ai pris bonne note, car cela me semble très important.

[Français]

Docteur Ayoub, êtes-vous d'accord avec notre lexique, et sinon, pourquoi? J'ai toujours dit que si nous définissons les termes au début d'une discussion, nous gagnons des heures, des jours et des mois de discussions. Nous nous apercevons souvent, après toutes ces discussions, que nous n'avions pas les mêmes définitions.

Vous avez livré un plaidoyer enlevé sur les soins palliatifs. Les membres du comité sont certainement tous sur la même longueur d'onde sur cette question. S'il y a un point où nous sommes tous d'accord, c'est bien celui-là. Vous prônez le développement des soins palliatifs, mais avez-vous des suggestions à nous faire à ce sujet? Ces soins sont dans une très grande mesure de compétence provinciale. Nous allons en traiter dans notre rapport du mois de juin, mais ce serait peut-être une bonne chose de connaître vos vues là-dessus afin de pouvoir rejoindre les autorités provinciales.

**M. Ayoub:** Le point important jusqu'à présent est l'absence de continuum dans l'administrations des soins palliatifs. De bonnes unités sont en place, mais il n'y a pas de liens entre ces unités, les centres locaux communautaires et les soins à domicile. Le manque de ressources financières est la raison de cette absence, d'où l'incapacité d'accorder du répit aux familles des malades. S'il y avait de meilleures ressources, on pourrait établir cette continuité entre les différentes sections de la prise en charge globale du patient en fin de vie.

**Senator Beaudoin:** In the field of palliative care, I don't believe we need more legislation; we simply need to better develop the services. Provinces should assume their responsibilities. We may want to suggest legislation, but it is not a federal jurisdiction.

You say we must ensure continuity and it is true. But we must also ensure co-operation between the federal government and the provinces. You're in a perfect position to tell us about the resources since you work in a hospital every day. Are the resources a problem?

[English]

**The Chairman:** Mr. Mahony, with regard to the issue of advance directives, I have to tell you that we had an entirely different pattern in the province of Manitoba. It was not the doctors who requested advance directive legislation. It was the Manitoba Society for Seniors. It was the legal fraternity. Quite frankly, doctors were not engaged in this issue at all. They became engaged after the fact and their position generally was one that supported the advance directive legislation because they thought that it led to clarity for what they could and could not do. I would welcome your comment on that.

**Mr. Mahony:** Concerning the issue of clarity, that has been suggested to me a number of times. What some people have said is that in end-of-life situations, in particular hospital situations where the family is involved, there is often conflict between different members of the family. There may be warring factions within a family, with one camp in support of the patient being disconnected and the other in support of the person being kept on life support. It has been suggested that advance directive legislation would clarify that, allowing one person to make the decision.

My belief is that passing a law is not always a solution to a problem, in particular when you are talking about family relationships where there are, if you like, latent conflicts, as well as open conflicts, some of which have been developing for years. When someone walks into the room and says, "I have dad's directive. I am in control here," I suggest that that will create as much litigation and as much conflict as existed before, if not more. What will now happen is that the parties will hire lawyers.

Being a lawyer and having practised law, I know what families can be like, and I know that the scope for conflict is almost infinite. I certainly agree that under the previous situation it was not good. When you have two or three people on each side of a hospital bed giving conflicting instructions to a doctor, there is no question that that is a messy situation. As a lay person once put it to me, dying is a messy business. I do not believe that a personal directive or advance directive, or whatever term is adopted by the province enacting the legislation, will improve or resolve that situation, but it may provide clarity as far as liability is concerned. We are coming back, perhaps, to the root of the matter. With respect to defining liability, it may provide some clarity. As for resolving conflicts and improving the situation that exists in some

**Le sénateur Beaudoin:** Dans le domaine des soins palliatifs, je ne pense pas que nous parlions de législation, nous dirons tout simplement qu'il faut les développer. Les provinces doivent prendre leurs responsabilités. Peut-être suggérerons-nous une législation, mais cela ne relève pas de nous.

Vous dites qu'il faut assurer une certaine continuité, c'est vrai. Il faut aussi assurer la collaboration entre le fédéral et les provinces. Sur la question des ressources, vous êtes bien placé pour en parler puisque vous êtes à l'hôpital tous les jours, existe-t-il un problème particulier à ce sujet?

[Traduction]

**La présidente:** Monsieur Mahony, en ce qui concerne les directives préalables, je dois vous dire que la situation est tout autre dans la province du Manitoba. Ce ne sont pas les médecins qui ont demandé le dépôt d'une mesure législative sur les directives préalables, mais plutôt la «Manitoba Society for Seniors» et les avocats. À vrai dire, les médecins n'ont aucunement pris part au débat. Ils se sont intéressés à la question après coup, et d'une façon générale ils appuyaient la loi sur les directives préalables, car, à leur avis, elle établissait plus clairement ce qu'ils pouvaient faire et ne pas faire. J'aimerais savoir ce que vous pensez de cela.

**M. Mahony:** On m'a souvent dit cela au sujet de la clarté. Certains affirment que, surtout à l'hôpital, lorsque la famille est présente, il y a souvent des conflits entre les différents membres de la famille. Il y a peut-être des factions en conflit au sein de la famille, un camp voulant que le patient soit débranché alors que l'autre souhaite qu'on le maintienne en vie. Certains estiment qu'une loi sur les directives préalables permettrait de clarifier ce genre de situation et de laisser une seule personne prendre la décision.

Pour ma part, j'estime que légiférer n'est pas toujours la solution, surtout lorsqu'il s'agit de relations familiales, lorsqu'il y a non seulement des conflits ouverts, mais aussi des conflits latents, dont certains couvent depuis des années. Si quelqu'un entre dans la chambre d'hôpital en disant: «J'ai les directives préalables de papa. C'est moi qui décide», il y aura autant de conflits qu'en l'absence de telles directives, sinon davantage, car alors les parties engageront des avocats.

Étant moi-même avocat et ayant pratiqué le droit, je sais ce que peuvent faire les familles et je sais que les possibilités de conflits sont presque infinies. Je suis d'accord pour dire que la situation qui prévalait auparavant n'était pas idéale. Lorsque deux ou trois personnes de chaque côté du lit d'hôpital donnent des instructions contradictoires au médecin, c'est une sale affaire. Mais comme un profane me l'a déjà fait remarquer, mourir est une sale affaire. Je ne crois pas que des directives préalables ou des directives personnelles, quel que soit le terme employé dans la loi provinciale, amélioreront ou corrigeront ce genre de situation, mais elles pourraient préciser la responsabilité. Nous revoilà au coeur du problème. Les directives préalables peuvent nous aider à mieux définir la responsabilité. Pour ce qui est de résoudre les



of those hospital rooms when a family member is dying, I do not think it will improve things one bit.

**The Chairman:** You seem to imply that, once a person signs an advance directive, it is there in perpetuity. I have changed my will at least six times throughout my life; because I had responsibilities for children at different stages of their lives, I therefore changed the will to accommodate that. I have also changed my advance directive three times since I signed my first advance directive in the Province of Manitoba. It is important to clarify that an advance directive is not a stagnant document; in fact, like a will, it can be a living document.

**Mr. Mahony:** Senator, you are very conscientious. I am not being facetious or sarcastic when I say that. Most people are not. As a lawyer, I was contacted about two years ago by someone who had been a client of my father and had made his will in 1958. For 30 years, he did not make a single change to the will. My point is that, as in everything else, a few people will be conscientious and update their directives and wills, but many people will not. The difference is that, if I forget to update an ordinary will, it will only affect the disposition of property or money, as a general rule. When a person does not update a directive, however, it may well determine the end of his or her life.

The stakes are much higher with a personal directive. It is a matter of life and death. An ordinary will and a power of attorney deals with property, but an advance directive deals with human life, far too important an issue to relegate to a single document.

A directive tries to encapsulate in a few lines a person's wishes about life and death, something that is ever-changing. We all have moments in our lives when we get depressed and lose hope, but we also have moments when we are prepared to go on. In many cases, people who sign advance directives will lose the opportunity to choose life.

Section 11 of the Alberta Personal Directives Act, which I know is one of several, provides that only a person who understands the nature and effect of revoking a directive may do so. There is essentially a capacity test which is a prerequisite to revocation. In other words, if you do not have the mental capacity to revoke that directive, you cannot do so. That is another way of saying that at a certain point the directive becomes permanent.

Coming back to what is at stake here, with directives it is generally a life and death issue, not a property issue. If Dad, Mom, and Uncle Sam forget to include me in their wills, no one will die as a result. I will be sorry that I did not get the house, but it is not a matter of life and death. Advance directives are often a case of life and death, and many directives will become a death sentence for people who would have revoked them, had they been as conscientious as you.

conflits et d'améliorer la situation qui existe dans certaines chambres d'hôpital où un patient est mourant, je ne crois pas que ce soit la solution.

**La présidente:** Vous semblez laisser entendre que les directives préalables sont gravées dans le marbre. J'ai changé mon testament au moins six fois dans ma vie; aux diverses étapes de la vie de mes enfants, j'ai modifié mon testament en conséquence. J'ai aussi changé mes directives préalables trois fois depuis que j'ai signé le premier document, au Manitoba. Il est important de préciser que les directives préalables ne constituent pas un document statique; en fait, comme un testament, c'est un document qui évolue.

**M. Mahony:** Sénateur, vous êtes très consciencieuse, et je le dis sans vouloir être facétieux ou sarcastique. La plupart des gens ne sont pas aussi consciencieux que vous. Étant moi-même avocat, il y a environ deux ans, un ancien client de mon père a communiqué avec moi. Il avait fait son testament en 1958. Pendant 30 ans, son testament est resté inchangé. Comme pour tout le reste, quelques-uns seront consciencieux et actualiseront leurs directives et leurs testaments, mais bien des gens ne le feront pas. La différence, c'est que si j'oublie de mettre à jour mon testament, cela n'influera généralement que sur la disposition de biens et d'argent. En revanche, lorsqu'une personne néglige d'actualiser ses directives préalables, cela peut très bien déterminer comment se déroulera la fin de sa vie.

Les enjeux sont beaucoup plus élevés dans le cas des directives préalables. C'est une question de vie et de mort. Le testament ordinaire et la procuration ne traitent que de biens, alors que les directives préalables traitent de la vie humaine, un enjeu beaucoup trop important pour qu'on le limite à un seul document.

Les directives préalables tentent de résumer en quelques lignes les souhaits d'une personne sur sa vie et sa mort, souhaits qui évoluent constamment. Nous avons tous connu des moments dans notre vie pendant lesquels nous avons été déprimés et désespérés, mais nous avons aussi des moments où nous sommes prêts à vivre malgré tout. Dans bien des cas, ceux qui signent des directives préalables n'auront pas la possibilité de choisir la vie.

L'article 11 de la loi sur les directives personnelles de l'Alberta, cette loi n'étant qu'une parmi tant d'autres, prévoit que seule une personne qui comprend la nature et les effets de la révocation d'une directive peut la révoquer. Essentiellement, l'aptitude est une condition préalable à la révocation. Autrement dit, si vous n'avez pas la capacité mentale de révoquer vos directives, vous ne pourrez le faire. Cela équivaut à dire qu'à partir d'un certain moment les directives deviennent permanentes.

Pour en revenir à l'enjeu, dans le cas des directives préalables il s'agit de vie et de mort, et non pas de biens. Si mon père, ma mère ou l'oncle Sam oublie de m'inclure dans son testament, personne n'en mourra. Je serai triste de ne pas avoir la maison, mais ce n'est pas une question de vie ou de mort. Les directives préalables signifient souvent la vie ou la mort: bon nombre de ces directives se transformeront en peine de mort pour ceux qui auraient voulu les révoquer, mais qui n'ont pas été aussi consciencieux que vous.



**The Chairman:** I have some questions about artificial hydration and nutrition, particularly with respect to the forcible treatment of patients with nutrition and hydration. We are all aware that, in order to be provided artificial hydration and nutrition, the patient must be connected to either an intravenous tube or a shunt. We cannot force-feed an individual by mouth. That is considered assault in the Criminal Code of Canada. Why is it any less an assault if we force-feed a person via tubes?

**Mr. Schadenberg:** In my report I referred to artificial nutrition and hydration with regard to the issue of want and need. The primary concern is for the incompetent. However, there is a difference if we refer to nutrition and hydration as medical treatment. That provides for the depressed and those who might be having a hard time with a health condition that may or may not be permanent but at this point in their lives has made them question whether they should continue to live.

The problem is that, if we call artificial nutrition and hydration medical treatment, it can be refused or withdrawn. When someone is competent to decide that they do not want any more food or fluids, because of their competency they may decide tomorrow to continue living because of a change in their life circumstances. Their competency allows them to continue.

In the case of the incompetent, there is a whole other dimension. For those who are in a persistent vegetative state, who may have severe disabilities, if this is called a medical treatment, especially for people who made an advance directive previous to their incompetency saying that they wanted no medical treatment in this situation, that would result in the end of artificial nutrition and hydration and in starvation and dehydration.

Oxygen is a different situation. If I deny you oxygen and you die, you die of the disease from which you were suffering. Oxygen is always available with no intervention. We always need food and fluids as well, but they must be taken or administered in some way, be it through a spoon, a tube, or whatever.

Therefore, it would very much put in jeopardy the lives of the incompetent to define artificial nutrition and hydration as medical treatment rather than as normal care. As I said in my presentation, care is based on need. Therefore, we do not force-feed someone who is dying. The issue here is not that of allowing someone whose body is shutting down to die naturally. The issue here involves people who are not otherwise dying, but who are incompetent, and whose family members decide to let them die more quickly and use this method to do so.

**Mr. Cameron:** The comparison with force-feeding may not be an exact analogy, because force-feeding implies a lack of consent, deliberately doing something against someone's will. Most of the situations in which artificial nutrition and hydration comes into question are situations in which the person is not conscious. There are cases where the body is shutting down and is no longer metabolizing. In those situations, nutrition and hydration can become burdensome.

**La présidente:** J'ai quelques questions à poser sur l'alimentation et l'hydratation artificielles, surtout concernant l'alimentation et l'hydratation forcées. Nous savons tous que l'alimentation et l'hydratation artificielles d'un patient se font par voie intraveineuse ou par un shunt. On ne peut forcer une personne à s'alimenter par la bouche. Cela constitue des voies de fait aux termes du Code criminel du Canada. Pourquoi l'alimentation forcée d'un patient par un tube ne constitue-t-elle pas des voies de fait?

**M. Schadenberg:** Dans mon mémoire, je parle de l'alimentation et de l'hydratation artificielles relativement aux souhaits et aux besoins. C'est une préoccupation surtout pour les personnes incapables. Toutefois, c'est différent si l'alimentation et l'hydratation sont un traitement médical. Ce traitement est administré aux personnes dépressives et à celles qui, en raison d'une maladie permanente ou non, se demandent si elles veulent continuer à vivre.

Lorsque l'alimentation et l'hydratation artificielles sont un traitement médical, on peut renoncer à ce traitement ou l'interrompre. Le patient qui est capable de décider qu'il ne veut plus d'aliments ou de liquides pourra le lendemain se raviser si les circonstances changent. Il a la capacité de décider.

La situation est bien différente pour les personnes incapables. Les personnes dans un état végétatif persistant, qui ont de graves handicaps et pour qui l'alimentation et l'hydratation artificielles sont considérées comme un traitement médical, surtout celles qui ont donné, avant de devenir incapables, des directives préalables dans lesquelles elles renonçaient au traitement médical dans une telle situation, pourraient voir leur alimentation et hydratation artificielles interrompues et mourir de faim et de déshydratation.

L'oxygène, c'est autre chose. Si on vous prive d'oxygène et que vous mourez, vous mourez de la maladie dont vous souffrez. L'oxygène est toujours disponible, sans intervention particulière. Nous avons toujours besoin d'aliments et de liquides aussi, mais ils doivent être pris ou administrés d'une façon ou d'une autre, à la cuiller, par un tube ou autrement.

Par conséquent, ce serait mettre en danger la vie des incapables que de définir l'alimentation et l'hydratation artificielles comme un traitement médical plutôt que comme des soins normaux. Comme je l'ai dit dans mon exposé, les soins sont dispensés en fonction des besoins. Par conséquent, nous n'alimenterons pas de force quelqu'un qui meurt. La question n'est pas de savoir s'il faut permettre à celui dont le corps cesse de fonctionner de mourir naturellement. La question est plutôt de savoir si on permet aux membres des familles des incapables qui ne sont pas mourants de les laisser mourir plus rapidement à l'aide de cette méthode.

**M. Cameron:** La comparaison avec l'alimentation forcée n'est pas la meilleure, car l'alimentation forcée implique l'absence de consentement, la décision d'agir délibérément contre le gré du patient. Généralement, lorsqu'il y a alimentation et hydratation artificielles, le patient n'est pas conscient. Ce sont des patients dont le corps cesse graduellement de fonctionner, dont le métabolisme a cessé. Dans ces cas, l'alimentation et l'hydratation peuvent devenir pénibles.

I think the same test must apply to artificial nutrition and hydration as is applied to all other treatments, and that is whether the benefit is greater than the burden.

Artificial nutrition and hydration could become burdensome in certain circumstances, but under most circumstances it is an ordinary necessity of life. It is not an extraordinary treatment unless you are in the end stage condition, where the body is rejecting the nutrition and hydration. Under most circumstances, I do not think it can be considered to be an extraordinary treatment, because all people have an inherent need for nutrition and hydration. It would not be considered force-feeding unless you were doing something against someone's will. I think most people would want to be fed, if they were going to be temporarily unconscious. There is a presumption that nutrition and hydration should continue to be administered unless it becomes positively contrary to clearly expressed will.

**The Chairman:** I think I understand what you are saying, but surely we need to clarify that it is a medical treatment. Sticking an IV in someone's arm or putting a shunt into their shoulder surely makes it a medical treatment. You are invading that person's body.

**Mr. Cameron:** The insertion of the shunt might be a medical treatment, but providing nutrition and hydration —

**The Chairman:** But you cannot provide it if you have not provided the shunt.

**Mr. Cameron:** The means may be a medical means but the end is something that is necessary in any condition of life. Merely because you use a medical technique to achieve that end does not make the end medical. The end is something that every living human being would be presumed to want. It is only the means that is medical, not the purpose for which it is provided.

**The Chairman:** My own experience with two dying parents was that, as they were dying, they did not want to eat or drink. It did not occur to me to feed them or give them drink artificially, when it was clear that they could take it naturally and chose not to.

**Mr. Cameron:** We are dealing with consent. You are potentially in a different situation. I am not talking about refusing treatment. I am talking about withdrawing treatment where there is no indication of consent.

**The Chairman:** There being no other questions, I wish to thank you all very much for your presentations this afternoon. They were very much appreciated.

The committee adjourned.

Le critère est le même pour l'alimentation et l'hydratation artificielles que pour les autres traitements: les bienfaits sont-ils supérieurs au fardeau que représente le traitement?

L'alimentation et l'hydratation artificielles peuvent devenir pénibles dans certaines circonstances, mais elles sont généralement un besoin ordinaire. Ce n'est pas un traitement extraordinaire, à moins que vous n'en soyez à la phase terminale, que votre corps ne rejette les aliments et les liquides. En général, je ne crois pas que cela puisse constituer un traitement extraordinaire, car tous ont un besoin inhérent d'aliments et de liquides. Cela ne sera pas considéré comme un traitement forcé, à moins que vous n'agissiez contre le gré du patient. À mon avis, la plupart des patients souhaiteraient être alimentés s'ils étaient inconscients. On présume que l'alimentation et l'hydratation se poursuivront à moins d'un ordre contraire clairement exprimé.

**La présidente:** Je crois que je vous comprends, mais il m'apparaît nécessaire de préciser qu'il s'agit d'un traitement médical. Faire une perfusion intraveineuse ou insérer un shunt dans l'épaule d'un patient, c'est un traitement médical. C'est une intrusion dans le corps du patient.

**M. Cameron:** L'insertion d'un shunt est peut-être un traitement médical, mais l'alimentation et l'hydratation...

**La présidente:** Mais elles ne peuvent se faire sans shunt.

**M. Cameron:** Le moyen employé est un moyen médical, mais il sert une fin nécessaire à la vie. Le fait d'employer une technique médicale pour arriver à cette fin ne signifie pas que la fin est médicale. La fin est la satisfaction d'un besoin, et on présume que c'est ce que voudrait tout être humain. C'est seulement la méthode qui est médicale, et non pas les raisons pour lesquelles le traitement est administré.

**La présidente:** D'après mon expérience auprès de mes parents mourants, je sais que pendant leur agonie ils ne voulaient ni manger, ni boire. Il ne m'est jamais venu à l'esprit de les alimenter ou de les hydrater artificiellement, puisqu'il était clair qu'ils pouvaient le faire naturellement et qu'ils avaient choisi de ne pas le faire.

**M. Cameron:** C'est une question de consentement. Cette situation est différente. Je ne parle pas de patients qui renoncent à un traitement. Je parle plutôt de l'interruption d'un traitement sans le consentement du malade.

**La présidente:** Puisqu'il n'y a pas d'autres questions, je remercie tous les témoins que nous avons accueillis cet après-midi. Nous vous savons gré de vos témoignages.

La séance est levée.



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#### WITNESSES—TÉMOINS

*From the Department of Health Canada:*

Carole Bouchard, Manager, Office of Controlled Substances:

Dr. Brian Gillespie, Senior Medical Advisor, Bureau of  
Pharmaceutical Assessment.

*From the Council of Canadians with Disabilities:*

Mr. Hugh Scher, Chair, Human Rights Committee.

*From the Campaign Life Coalition:*

Mr. Peter Ryan, Director (New Brunswick).

*From the Euthanasia Prevention Coalition of Ontario:*

Mr. Alex Schadenberg, Executive Director.

*From the Alliance for Life Ontario:*

Ms. Jacki Jeffs, Executive Director.

*From Care in Dying:*

Mr. Mark Cameron, coordinator:

Dr. Joseph Ayoub, oncologist, Institut du cancer de Montréal.

*From Alberta Life Foundation:*

Mr. James Mahony.

*Du ministère de Santé Canada:*

Carole Bouchard, gestionnaire, Bureau des substances contrôlées:

Dr Brian Gillespie, conseiller médical spécial, Bureau de  
l'évaluation des produits pharmaceutiques.

*Du Conseil des Canadiens avec déficiences:*

Hugh Scher, président, Comité des droits de la personne.

*De Campaign Life Coalition:*

M. Peter Ryan, directeur (Nouveau-Brunswick).

*De la Euthanasia Prevention Coalition of Ontario:*

M. Alex Schadenberg, directeur exécutif.

*De l'Alliance pour la vie (Ontario):*

Mme Jacki Jeffs, directeur exécutif.

*De Soutien aux mourants:*

M. Mark Cameron, coordonnateur:

Dr Joseph Ayoub, oncologue, Institut du cancer de Montréal.

*De l'Alberta Life Foundation:*

M. James Mahony.



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Second Session  
Thirty-sixth Parliament, 1999-2000

Deuxième session de la  
trente-sixième législature, 1999-2000

SENATE OF CANADA

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SÉNAT DU CANADA

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*Standing Senate Committee on Social Affairs,  
Science and Technology*

*Comité sénatorial permanent des affaires sociales,  
des sciences et de la technologie*

*Proceedings of the Subcommittee to*

*Délibérations du sous-comité de*

**Update “Of Life  
and Death”**

**Mise à jour de  
«De la vie et de la  
mort»**

*Chair:*  
The Honourable SHARON CARSTAIRS

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*Présidente:*  
L'honorable SHARON CARSTAIRS

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Tuesday, March 21 2000

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Le mardi 21 mars 2000

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Issue No. 7

Fascicule n° 7

**Seventh meeting on:**

Examination of the developments since the tabling in  
June 1995 of the final report of the Special Senate  
Committee on Euthanasia and Assisted Suicide,  
entitled, “Of Life and Death”

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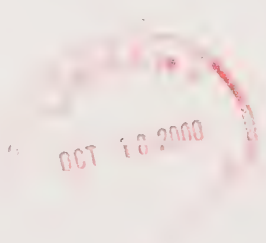
**Septième réunion concernant:**

L'étude des faits nouveaux survenus depuis le dépôt,  
en juin 1995, du rapport final du comité sénatorial  
spécial sur l'euthanasie et l'aide au suicide intitulé:  
«De la vie et de la mort»

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WITNESSES:  
(See back cover)

TÉMOINS:  
(Voir à l'endos)



THE SUBCOMMITTEE TO UPDATE  
“OF LIFE AND DEATH”

The Honourable Sharon Carstairs, *Chair*

The Honourable Gérald-A. Beaudoin, *Deputy Chair*

and

The Honourable Senators:

\* Boudreau, P.C.  
(or Hays)  
Corbin  
Keon

\* Lynch-Staunton  
(or Kinsella)  
Pépin

\* *Ex Officio Members*

(Quorum 3)

LE SOUS-COMITÉ DE MISE À JOUR DE  
«DE LA VIE ET DE LA MORT»

*Présidente:* L'honorable Sharon Carstairs

*Vice-président:* L'honorable Gérald-A. Beaudoin

et

Les honorables sénateurs:

\* Boudreau, c.p.  
(ou Hays)  
Corbin  
Keon

\* Lynch-Staunton  
(ou Kinsella)  
Pépin

\* *Membres d'office*

(Quorum 3)

**MINUTES OF PROCEEDINGS**

OTTAWA, Tuesday, March 21, 2000

(9)

[English]

The Subcommittee to update "Of Life and Death" met this day in room 257, East Block, at 10:02 a.m., the Honourable Sharon Carstairs, Chair, presiding.

*Members of the committee present:* The Honourable Senators Beaudoin, Carstairs, Corbin, Keon and Pépin (5).

*Other senator present:* The Honourable Senator Roche (1).

*In attendance:* Mollie Dunsmuir and Nancy Miller-Chénier, Research Officers, Research Branch, Library of Parliament.

*Also in attendance:* The official reporters of the Senate.

**WITNESSES:**

*From the Catholic Health Association of Canada:*

Sister Annette Noël, Vice-Chair, Board of Directors;

Dr. Elizabeth Latimer, Professor, Department of Family Medicine, McMaster University;

Dr. Richard Haughian, President.

*From the Barreau du Québec:*

Ms Suzanne Vadboncoeur, lawyer, Director, Research and Legislation Division;

Ms Edith Deleury, lawyer, Professor, Université Laval;

Mr. Jean-Pierre Ménard, lawyer.

Pursuant to its Order of Reference adopted in the Standing Senate Committee on Social Affairs, Science and Technology on Monday, November 29, 1999, the subcommittee continued its examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death". (*For full text of Order of Reference please refer to Issue No. 1.*)

The Chair made an opening statement.

Sister Annette Noël, Dr. Elizabeth Latimer and Dr. Richard Haughian each made a statement.

Ms Suzanne Vadboncoeur, Ms Edith Deleury and Mr. Jean-Pierre Ménard each made a statement

The witnesses answered questions.

The Barreau du Québec agreed to send a brief regarding other elements of the committee's reports.

**PROCÈS-VERBAL**

OTTAWA, le mardi 21 mars 2000

(9)

[Traduction]

Le sous-comité de la mise à jour de «De la vie et de la mort» se réunit aujourd'hui, à 10 h 02, dans la pièce 257 de l'édifice de l'Est, sous la présidence de l'honorable Sharon Carstairs (*présidente*).

*Membres du comité présents:* Les honorables sénateurs Beaudoin, Carstairs, Corbin, Keon et Pépin (5).

*Autre sénateur présent:* L'honorable sénateur Roche (1).

*Également présentes:* Mollie Dunsmuir et Nancy Miller-Chénier, attachées de recherche, Direction de la recherche parlementaire, Bibliothèque du Parlement.

*Aussi présent:* Les sténographes officiels du Sénat.

**TÉMOINS:**

*De l'Association catholique canadienne de la santé:*

Soeur Annette Noël, vice-présidente, conseil d'administration;

La docteure Elizabeth Latimer, professeure, Département de médecine familiale, Université McMaster;

Le docteur Richard Haughian, président.

*Du Barreau du Québec:*

Mme Suzanne Vadboncoeur, avocate, directrice, Service de la recherche et de la législation;

Mme Edith Deleury, avocate, professeure, Université Laval;

M. Jean-Pierre Ménard, avocat.

Conformément à l'ordre de renvoi adopté par le comité sénatorial permanent des affaires sociales, des sciences et de la technologie, le lundi 29 novembre 1999, le sous-comité poursuit l'étude des faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort». (*Voir le texte complet de l'ordre de renvoi dans le fascicule n° 1.*)

La présidente fait une déclaration.

Soeur Annette Noël, la Dre Elizabeth Latimer et le Dr Richard Haughian font tous une déclaration.

Mme Suzanne Vadboncoeur, Mme Edith Deleury et M. Jean-Pierre Ménard font tous une déclaration.

Les témoins répondent aux questions.

Le Barreau du Québec convient d'envoyer un mémoire au sujet d'autres éléments des rapports du comité.



At 11:56 a.m., the committee adjourned to the call of the Chair.

À 11 h 56, le comité suspend ses travaux jusqu'à nouvelle convocation de la présidence.

*ATTEST:*

*ATTESTÉ:*

*La greffière du comité,*

Heather Lank

*Clerk of the Subcommittee*

**EVIDENCE**

OTTAWA, Tuesday, March 21, 2000

The Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 10:02 a.m. to examine the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death".

**Senator Sharon Carstairs** (*Chairman*) in the Chair.

[*English*]

**The Chairman:** Honourable senators, today is the seventh day of hearings under our mandate to update the unanimous recommendations of the Of Life and Death Report of the Special Senate Committee on Euthanasia and Assisted Suicide.

I would remind honourable senators and witnesses, and those who are following the committee on television, that this committee is not reopening the debate on assisted suicide or euthanasia. It is dealing strictly with the areas of the report where the committee made unanimous recommendations. I would ask that everyone bear that in mind as we proceed through these hearings.

We have two groups before us today. They are the Catholic Health Association of Canada and the Barreau du Québec. Welcome. I would remind each group that you have a maximum of 15 minutes to make your presentation. Please proceed.

[*Translation*]

**Sister Annette Noël, Vice-President, Board of Directors, Catholic Health Association:** The Catholic Health Association is a national Christian association supportive of health care in the tradition of the Roman Catholic Church. As the national voice for Catholic health care, we actively promote health in all its aspects: physical, emotional, spiritual and social. Our association encourages all activities designed to promote wellness, prevent disease and cure sickness.

Our membership comprises eight provincial associations, 34 owners of health care organizations, 127 hospitals and long-term care facilities and homes, health care professionals and affiliate organizations and individuals.

Many of CHAC's member hospitals and homes are actively involved end-of-life the care and offer palliative care services. The Association has articulated ethical norms for the care of dying persons. They are included in a health ethics guide published by the Association. We have bilingual versions of the chapter covering end-of-life care.

The Association appeared before the Special Senate Committee on Euthanasia and Assisted Suicide in 1994. We greatly appreciate

**TÉMOIGNAGES**

OTTAWA, le mardi 21 mars 2000

Le sous-comité de mise à jour de «De la vie et de la mort» du comité sénatorial permanent des affaires sociales, des sciences et de la technologie se réunit aujourd'hui, à 10 h 02, en vue d'étudier les faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort».

**Le sénateur Sharon Carstairs** (*présidente*) occupe le fauteuil.

[*Traduction*]

**La présidente:** Honorables sénateurs, aujourd'hui marque le septième jour des audiences tenues dans le cadre de notre mandat visant à mettre à jour les recommandations unanimes du rapport du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort».

Je vous rappelle, de même qu'aux témoins et à ceux qui suivent nos audiences, que le sous-comité ne reprend pas le débat sur l'aide au suicide et l'euthanasie. Il se concentre uniquement sur les parties du rapport où le comité initial avait des recommandations unanimes. Je vous demanderais de ne pas l'oublier.

Nous entendrons aujourd'hui deux groupes de témoins. Il s'agit de l'Association catholique canadienne de la santé et du Barreau du Québec. Bienvenu. Je rappelle à nos témoins qu'ils disposent d'au plus 15 minutes pour présenter leur exposé. Je vous laisse la parole.

[*Français*]

**Sœur Annette Noël, vice-présidente, conseil d'administration, Association catholique de la santé:** L'Association catholique canadienne de la santé est une association chrétienne nationale. Elle soutient des soins de santé dans la tradition de l'église catholique romaine. Elle est donc la voie nationale des soins de santé catholiques, capable de promouvoir la santé sous toutes les dimensions de la personne humaine, soit physique, émotionnelle, spirituelle et sociale. L'association encourage toute activité pour promouvoir le bien-être, la prévention et la guérison.

Parmi nos membres, nous comptons 8 associations provinciales, 34 membres propriétaires d'organismes de soins de santé, 127 hôpitaux et centres de soins de longue durée et d'hébergement, des professionnels de la santé, des organismes et des membres affiliés.

Plusieurs de nos hôpitaux et centres sont activement impliqués dans des soins en fin de vie et offrent des services en soins palliatifs. L'association a articulé des normes d'éthique en soins de fin de vie. Elles sont insérées dans un guide d'éthique à la santé publié par l'association. Nous avons des versions bilingues de ce chapitre des soins en fin de vie.

Nous avons déjà comparu en tant qu'association devant un comité spécial du Sénat en 1994 lorsque nous avons traité de

the opportunity to appear before this Senate committee as part of an update on a topic that is very dear to us: life and death.

Advances in science and technology are dramatically improving our ability to cure illness, ease suffering and prolong life. That is wonderful. At the same time, these advances also raise new ethical questions concerning end-of-life care. In the face of such issues, the CHAC emphasizes the necessity of maintaining a balance between two important obligations.

We are obliged not to intentionally kill someone; as a result, assisted suicide and euthanasia are not acceptable options. At the same time, we are not obliged to use life-sustaining procedures which would impose burdens on individuals or families which are out of proportion with the benefits to be gained from such procedures.

Having raised these considerations, I will now give the floor to Dr. Latimer who will continue our remarks.

[English]

**Dr. Elizabeth Latimer, Professor, Department of Family Medicine, McMaster University; Presenter, Catholic Health Association of Canada:** At the outset, I should like to say that it is an honour to be here. I had the honour to testify before you in 1994 and it is a great honour on this day to be a presenter with the Catholic Health Association of Canada.

On behalf of the association and myself, we would like to congratulate you on revisiting these issues for an update. It has been very affirming for us that you have a continued interest in these issues and I would ask you to maintain that interest in future.

We have entitled our brief "The Luck of the Draw", which is a phrase that we have chosen to illustrate the very vital point that the care of dying people in Canada will depend, at the present time, to a very large degree on luck. We would like to illustrate for you what that luck might be.

You have the brief before you and, on page 5, I should like to begin by highlighting some of the issues in care for a woman named Mrs. J.H., who is 63 years old and has end-stage heart failure in Canada. I wish to highlight how Mrs. J.H. has "good luck" in her end-stage care.

I know you will have an opportunity to read this brief afterwards but, in essence, Mrs. J.H. begins by having a cardiologist, who is able to talk with her, who is able to order medications for her shortness of breath, her suffocation, her end-stage heart failure. The cardiologist helps her make decisions. The hospital in which she is receiving her care has staffed an interdisciplinary palliative care service and they are called to be involved in her care.

Mrs. J.H.'s luck continues to hold, in that her particular home care community has not suffered too badly under the downsizing of economics in health care in Canada, and they are also assigning

l'euthanasie et du suicide assisté. Nous apprécions énormément cette opportunité de nous présenter devant ce comité du Sénat pour la mise à jour d'un thème qui nous est cher, la vie et la mort.

La science et la technologie modernes font en sorte que nous sommes mieux habilités pour guérir la maladie, soulager la souffrance et prolonger la vie. Cela est merveilleux. Cela implique de grandes questions éthiques, surtout en ce qui concerne des soins en fin de vie. C'est dans ces situations et face à de telles questions que l'association voit la nécessité de maintenir un équilibre entre deux obligations importantes.

D'une part, personne ne peut enlever la vie de façon intentionnelle à une autre personne. Par conséquent, l'euthanasie et le suicide assisté ne peuvent être considérées des options, car elles sont inacceptables. D'autre part, nous ne sommes pas obligés de maintenir des procédures qui prolongent inutilement la vie, des procédures qui imposeraient un fardeau à l'individu ou à la famille, sans aucun bénéfice de vie aux personnes.

Suite à ces considérations, je laisse maintenant la parole au docteur Latimer qui poursuivra cette réflexion.

[Traduction]

**La docteure Elizabeth Latimer, professeure, département de médecine familiale, Université McMaster; témoin, Association catholique canadienne de la santé:** Permettez-moi de dire d'emblée que c'est un honneur pour moi de venir vous rencontrer. J'ai eu le plaisir de témoigner devant vous en 1994 et j'ai le privilège aujourd'hui de représenter l'Association catholique canadienne de la santé.

Au nom de l'association et en mon nom propre, je tiens à vous féliciter de l'examen que vous faites de ces questions dans le cadre d'une mise à jour. Nous sommes très encouragés de ce que vous continuez de vous intéresser à ces questions et je vous demande de continuer à vous y intéresser à l'avenir.

Nous avons intitulé notre mémoire «Une question de chance?». Nous avons choisi ce titre pour illustrer le fait très important qu'à l'heure actuelle, les soins aux mourants, au Canada, sont dans une très grande mesure une question de chance. Nous aimerions vous en donner un exemple.

Dans le mémoire qui vous a été présenté, à la page 4, je vais commencer par vous donner les points saillants des soins offerts à une femme du nom de Mme J.H., âgée de 63 ans, qui souffre d'une maladie cardiaque en phase terminale au Canada. Cet exemple montre en quoi Mme J.H. est chanceuse dans les soins de fin de vie qui lui sont dispensés.

Je sais que vous aurez l'occasion de lire notre mémoire plus tard, mais en résumé, Mme J.H. reçoit des soins d'un cardiologue qui est capable de discuter avec elle, qui peut lui prescrire des médicaments pour ses problèmes respiratoires, ses problèmes de suffocation et ses problèmes cardiaques en phase terminale. Ce cardiologue l'aide à prendre des décisions. L'hôpital où elle reçoit des soins possède une équipe pluridisciplinaire de soins palliatifs qui participe à son traitement.

Mme J.H. continue d'avoir de la chance. Les services communautaires de soins à domicile de sa localité n'ont pas trop souffert des compressions budgétaires ni de la restructuration des



a high priority to palliative care needs in their community. The result is that she has services available to her through home care. She also has a family doctor who has had some educational training in palliative care and has embraced a desire to care for her palliative care patients at home.

The community has also designed and funded an agency inter-institutional palliative program, which allows a variety of settings for care, so that Mrs. J.H. can be admitted to a unit for palliative care at end of life if her needs require that. You can see that, with home care support, a good family doctor, palliative care awareness all around and the funding of a palliative care team to go to the home to help her family doctor, she is indeed able to go home and is at home for three weeks with excellence in care.

When her shortness of breath, which in end-stage heart failure can approach suffocation, becomes more problematic, she becomes somewhat agitated and delirious and requires admission to a palliative care setting, which is able to happen for her because those arrangements and facilities are in place.

Over the page, on page 6, we can see that key components of the “luck of the draw” include the nature of her illness. At the present time in Canada, palliative care is usually associated with cancer. For the association, I have intentionally chosen a lady with end-stage heart failure so that we can reiterate that there are many people who need palliative end-of-life care who may not receive it because their diagnosis is not cancer. The lead physician on Mrs. J.H.’s primary attending health care team was a cardiologist; however, she had many doctors who embrace the palliative care philosophy.

I have already mentioned settings for care. A community requires these.

Where there is a palliative care program, there will be services for people. In the vast majority of communities in Canada where these do not exist, needed services will not be available.

Mrs. J.H. has doctors who are assuming her care and will care for her.

Again, there is an elaboration of those on page 7, including number 3, effective home care services and palliative care expertise to go to her home.

On page 8, there is a radically different scenario. If we were to take any of the five key components, which are listed on page 6, out of Mrs. J.H.’s care, the scene would be dramatically different, with ineffective symptom control and fractured care. For example, if she did not have aware physicians or an aware health care team, certain things would not be able to happen for her. If there was no in-patient facility for her to go to, she would need to return to an emergency room, suffer unrelieved symptoms, and possibly die in

soins de santé au Canada. En outre, sa collectivité accorde un degré de priorité élevé aux besoins en matière de soins palliatifs. Cela permet à Mme J.H. d’obtenir des services à domicile. Son médecin de famille a également reçu une formation en soins palliatifs et souhaite offrir ce genre de soins à ses patients à domicile.

Sa localité a également conçu et financé un programme interinstitutionnel de soins palliatifs qui permet d’offrir ces soins dans divers milieux. Cela permettra à Mme J.H. d’être admise dans une unité de soins palliatifs de fin de vie, si elle en a besoin. Grâce aux soins qu’elle peut recevoir à domicile, à un bon médecin de famille, à une sensibilisation générale de son milieu aux soins palliatifs et au financement d’une équipe de soins palliatifs qui peut aider son médecin de famille dans les soins à domicile, Mme J.H. peut retourner chez elle. Elle y demeure pendant trois semaines et reçoit d’excellents soins.

Lorsque ses problèmes respiratoires s’aggravent, et dans une maladie cardiaque en phase terminale, ces problèmes peuvent aller jusqu’à la suffocation, Mme J.H. devient agitée et commence à délirer. Elle doit être admise dans une unité de soins palliatifs. Cela lui est possible grâce aux dispositions qui ont été prises et à l’existence des installations nécessaires.

À la page 5, vous pouvez voir que les éléments de sa «chance» sont également liés à la nature de sa maladie. À l’heure actuelle, au Canada, les soins palliatifs sont très souvent associés aux cancéreux. Aux fins de notre mémoire, c’est à dessein que j’ai choisi le cas d’une dame souffrant d’une maladie cardiaque en phase terminale de façon à pouvoir répéter qu’un grand nombre de gens qui auraient besoin de soins palliatifs de fin de vie ne reçoivent pas ces soins parce qu’ils souffrent d’une autre maladie. Le principal médecin de l’équipe de soins de santé primaires de Mme J.H. était un cardiologue; elle a néanmoins reçu les soins de bon nombre de médecins sensibilisés aux soins palliatifs.

J’ai déjà parlé du lieu de traitement. Les localités ont besoin des installations nécessaires.

Les gens ne peuvent recevoir de soins palliatifs que s’il existe des programmes pour cela. Dans une vaste majorité de localités canadiennes, il n’existe pas de programmes et les soins nécessaires ne sont pas dispensés.

Mme J.H. reçoit des soins de médecins responsables qui continueront de s’occuper d’elle.

Nous continuons notre explication à la page 6 de notre mémoire, entre autres au numéro 3, où nous parlons de soins et de compétences en soins palliatifs qui peuvent être dispensés à domicile.

À la page 7, nous vous présentons un scénario complètement différent. Si nous éliminions les cinq éléments principaux, listés à la page 5, des soins dispensés à Mme J.H., le tableau serait entièrement différent. Le contrôle des symptômes serait inefficace et les soins seraient fractionnés. Par exemple, elle ne pourrait recevoir certains soins si elle n’avait pas des médecins et une équipe de soignants sensibilisés aux soins palliatifs. S’il n’existait pas d’unité de soins palliatifs, elle aurait probablement dû

an emergency room, in a setting that would be opposite to her needs.

I should like to move now to page 9, where we list recommendations under six headings, beginning with care for patients and families, which we have placed as a number 1 issue in Canada. There are a number of points indicated, including the fact that 75 per cent of Canadians still die in institutions, and services there are grossly underfunded and grossly lacking.

Restructuring and downsizing of our health care delivery system across Canada has resulted in a downsizing of palliative care services also — services that were never effectively funded in the first place. At the same time, downsizing has created a situation where surgeons and other hospital services would welcome alternate settings for care so that palliative patients might receive needed services in settings suited to their needs.

Coordinated programs are still quite rare. No province in Canada has a policy for palliative care with necessary funding, and partial palliative care, as indicated, may exist more frequently than is effective for patient care.

Our recommendations for action include policy development at the federal and provincial levels, with funding requisite to set in place the palliative care services that are necessary. We believe that palliative programs should be developed and should exist in every community, urban or rural, in Canada. We believe that the palliative care standards, as developed by the Canadian Palliative Care Association, should be embraced, and we wish to see them embraced at the level of health ministries, hospitals, community care, and long-term care settings.

We would also like to see these standards as mandatory for hospital accreditation in Canada. We would like to see the obstacles impeding good palliative care addressed. At every community and every organization, the obstacles will vary depending, but along with conjoint planning for a program each centre must identify its own obstacles to effective care.

I would now like to move to our second major set of recommendations, under the general heading of "education". Suffice it to say that the recommendations are in your brief and here on the overhead as well. As you have heard, there are 16 medical schools in Canada, one or two of whom have minimal palliative care education. The remainder do not. We would like to recommend that there be a level of education for all medical trainees as undergraduates, in residency training, and similarly in nursing and other professional groups. This is fundamental to moving ahead in end-of-life care in Canada.

retourner aux urgences, ses symptômes n'auraient pas reçu de soulagement et elle serait probablement morte dans une salle d'urgence, dans un milieu contraire à ses besoins.

Passons maintenant à la page 8. On y trouve la liste de nos recommandations sous six rubriques, dont la première est intitulée Soins dispensés aux patients et à leur famille. Pour nous, c'est le principal problème au Canada. Nous y mentionnons un certain nombre d'arguments, y compris le fait que 75 p. 100 des Canadiens meurent encore dans des établissements, que les services ou bien n'existent pas, ou bien sont ridiculement sous-financés.

La restructuration et les compressions effectuées dans les hôpitaux de tout le Canada ont également provoqué une réduction des services de soins de santé — des services qui au départ n'ont jamais été suffisamment financés. Ainsi, les chirurgiens et les autres services des hôpitaux seraient heureux de disposer d'autres outils pour pouvoir offrir aux patients requérant des soins palliatifs les services nécessaires dans un environnement adapté à leurs besoins.

Les programmes coordonnés sont encore trop rares. Aucune province canadienne n'a encore adopté de politique en matière de soins palliatifs ni ne finance de façon suffisante ce genre de soins. Comme nous l'indiquons, on dispense parfois des services partiels de soins palliatifs, mais ces soins sont insuffisants pour les patients.

Dans les mesures que nous recommandons, nous préconisons que le fédéral et les provinces élaborent une politique de services de soins palliatifs et avancent les fonds nécessaires à ces services. Nous croyons que toutes les localités du Canada, qu'elles soient urbaines ou rurales, devraient disposer de programmes de soins palliatifs. Nous croyons également que les normes de soins palliatifs que l'Association canadienne des soins palliatifs est en train d'élaborer devraient être adoptées et appuyées à tous les niveaux, depuis les ministères de la Santé jusqu'aux hôpitaux en passant par les établissements de soins communautaires et de longue durée.

Nous souhaitons également que ces normes soient une composante obligatoire du processus d'accréditation des hôpitaux au Canada. Nous souhaitons que soient supprimés les obstacles qui nuisent à des soins palliatifs de bonne qualité. Ces obstacles varient d'une collectivité à l'autre et d'un organisme à l'autre, mais grâce à la planification conjointe d'un programme, chaque centre doit identifier les obstacles qui empêchent d'offrir des soins efficaces.

Permettez-moi de passer maintenant à nos autres recommandations, à la rubrique Éducation. Les recommandations qui se trouvent dans notre mémoire sont également dans ces transparents. Comme on vous l'a dit, il existe 16 écoles de médecine au Canada. Une ou deux de ces écoles offrent une formation minimale en soins palliatifs. Les autres ne l'enseignent pas. Nous recommandons que tous les étudiants du domaine médical reçoivent des cours de soins palliatifs, lorsqu'ils étudient au premier cycle, et lorsqu'ils reçoivent leur formation en résidence. Un enseignement semblable devrait être dispensé aux infirmiers et infirmières et autres professionnels de la santé. C'est



We would also like major colleges for the professions, nationally and in the provinces, to identify a basic knowledge and educational standard, which all trainees must meet and which all practising physicians must meet in end-of-life palliative care.

Under the heading “research”, we would draw your attention to the brief. It is sufficient to say that we support and recommend this, our belief being that it would flow out of effective, fully developed clinical programs. As well, funding bodies need support and encouragement to fund in this area.

Regarding advanced health directives, again, this is detailed in the brief. We would like to say that they are important. They are not a panacea for good care by any means; perhaps their major role is in encouraging families and sick people to begin to talk, even in informal dialogue, about their wishes at the end of life.

In the area of life-sustaining treatments, our emphasis here would be that decisions for cessation and non-initiation of therapies are being made in Canada on a daily basis. Decision making is an important and complex process. There are no simple, hasty solutions to guiding health care teams in this area. What is required is compassionate, effective, interpersonal communication. As such, we hearken back to the huge educational need in Canada for health care teams in all aspects of end-of-life palliative care. We believe that education and preparation would enhance the whole process of life-sustaining treatment issues.

The last topic is sedation practices. As we say in the brief, some patients require sedation at end-of-life care. Dr. Chater of Ottawa, who is referenced in our brief, suggests a change of title in this area to “sedation practices in end-of-life care for the treatment of symptoms.” This wording would be a more appropriate approach. She has written a paper that we suggest may be important in this area.

Again, sedation practices come out of a good knowledge base and clinical practice in palliative symptom control. This brings us back to our emphasis on the need for professional health education. If people know how to provide symptom control and emotional support and if palliative care expert teams exist in hospital and in the community, which we are also recommending, then sedation practices will be ethical and will be carried out for the intended reasons — that is, symptom control and a restful state for a sick person at the end of life.

essentiel si l'on veut faire des progrès dans les soins de fin de vie au Canada.

Nous voudrions aussi que les principaux ordres des professions de la santé, à l'échelle tant nationale que provinciale, établissent une norme minimale de connaissances et de formation relative aux soins palliatifs de fin de vie à laquelle tous les stagiaires et tous les médecins en exercice devraient satisfaire.

En ce qui a trait à la recherche, nous vous invitons à lire ce que nous disons dans le mémoire. Je me contenterai de souligner que nous appuyons et préconisons la recherche qui, à notre avis, découle naturellement de programmes cliniques efficaces et complets. En outre, les organismes de financement ont besoin d'appui et d'encouragement pour ce qui est de financer la recherche dans ce domaine.

Notre position sur les directives préalables concernant les soins de santé se trouvent détaillées aussi dans notre mémoire. Ces directives sont importantes. Elles ne sont pas une garantie de soins de qualité, loin de là; leur principale contribution est peut-être d'encourager les malades à discuter avec leurs familles, même de façon informelle, de ce qu'ils souhaitent comme soins au terme de leur vie.

En ce qui concerne les traitements essentiels au maintien de la vie, nous tenons à insister sur le fait que tous les jours, au Canada, on décide s'il y a lieu d'entreprendre ou de poursuivre une action thérapeutique. La prise de décision est un processus important et complexe. Il n'y a pas de solutions simples et rapides qui permettent de guider la prestation des soins de santé dans ce domaine. D'où l'importance de la compassion et de communication interpersonnelles efficaces. C'est pourquoi nous insistons sur les lacunes énormes qui existent au Canada pour ce qui est de former des équipes de soins de santé bien conscientes de tous les aspects des soins palliatifs de fin de vie. Nous sommes d'avis qu'une formation et une préparation efficaces permettraient de mieux aborder toutes les questions relatives aux traitements essentiels au maintien de la vie.

Le dernier sujet est celui de la sédation. Comme nous le disons dans notre mémoire, certains malades ont besoin de sédatifs dans le cadre des soins qu'ils reçoivent au terme de leur vie. Le docteur Chater, d'Ottawa, dont le nom est évoqué dans notre mémoire, propose qu'on parle plutôt de «pratiques de sédation dans les soins de fin de vie pour le soulagement des symptômes». Cette formulation reflète une approche qui serait plus acceptable. Le docteur Chater a rédigé un document sur le sujet qui pourrait vous être utile.

Les pratiques de sédation découlent d'une bonne base de connaissances et de bonnes pratiques cliniques pour ce qui est du soulagement des symptômes dans les soins palliatifs. Cela nous ramène encore à l'importance de la formation des professionnels de la santé. Si les soignants savent soulager les symptômes et apporter le soutien affectif voulu et s'il existe dans les hôpitaux et dans la collectivité des équipes de spécialistes des soins palliatifs, comme nous le recommandons également, les pratiques de sédation seront conformes à la déontologie et seront utilisées pour les fins voulues, c'est-à-dire pour calmer les malades et soulager leurs symptômes au terme de leur vie.



**Dr. Richard Haughian, President, Catholic Health Association of Canada:** Honourable senators, in conclusion, the Catholic Health Association of Canada affirms the vision that was presented by the unanimous recommendations of the early report. It contains a vision of care of those who are dying, a vision that we strongly affirm.

Our brief is showing that some progress has been made towards those recommendations, but a lot still has to be done. We are strongly suggesting that palliative care not be looked upon as an add-on but as an integrated part of the health care delivery system. This, in fact, becomes a model not just for end-of-life care but for care throughout the whole system. I know we are not the first ones to say that, but we strongly emphasize that.

Lastly, we strongly believe that this fits in very much with the values of Canadians, that we are known for our humanitarian interest, for concern about those in need, and we should really be acting to reflect this as a national policy for those who are dying. We want to be known, really, in the international community for what we are doing to care for those who are dying.

The Catholic Health Association of Canada again thanks the Senate for this opportunity to present to you. We hope that your report will be strong. If there is any way in which we as an association can work with you in implementing recommendations we would be glad to do that.

[Translation]

**Ms Suzanne Vadboncoeur, Director, Research and Legislation Division, Barreau du Québec:** I am pleased to be here on behalf of the Barreau du Québec in response to your invitation to deal specifically with chapter 6 of the Senate report which deals with agreements and advance directives. I am accompanied on my left by Ms Edith Deleury, professor of family law and human rights law at Laval University, who is a member of several ethics committees. On my right is Mr. Jean-Pierre Ménard, who is a lawyer in private practice, a professor and a medical specialist.

We are here to discuss the current situation in Quebec as regards advance directives. I want to start by apologizing to people who are not legal experts: our presentation will perhaps seem a bit more technical than the Association's presentation was. I do hope, however, that we can word the presentation in a way that is understandable.

In Quebec, with respect to legislative or regulatory provisions, I will describe what guides citizens as well as medical teams in terms of care. Ms Deleury will tell you a little bit more about the mandate in case of inability, which is a Quebec creation that has existed for 10 years in the Civil Code, and Mr. Ménard will tell you about a very flexible vehicle that we have with the Civil Code in Quebec, one that is a little bit broader than the living will.

**Le docteur Richard Haughian, président, Association catholique canadienne de la santé:** En conclusion, honorables sénateurs, l'Association catholique canadienne de la santé entérine la vision que reflètent les recommandations unanimes du rapport antérieur. Ce rapport décrit une vision des soins à donner aux mourants, vision que nous appuyons entièrement.

Dans notre mémoire, nous disons que des progrès ont été réalisés en vue de la mise en oeuvre de ces recommandations, mais qu'il reste encore beaucoup à faire. Nous recommandons vivement que les soins palliatifs soient considérés non pas comme un élément qui vient s'ajouter au système de soins de santé, mais comme partie intégrante de ce système. Ce modèle devrait d'ailleurs s'appliquer non pas seulement aux soins de fin de vie, mais aux soins donnés dans l'ensemble du système de santé. Je sais que nous ne sommes pas les premiers à le dire, mais nous tenons à bien insister là-dessus.

Enfin, nous sommes fermement d'avis que c'est là un modèle qui coïncide parfaitement avec les valeurs des Canadiens qui sont connus pour leur intérêt humanitaire et leur solidarité avec ceux qui sont dans le besoin, et qu'il faudrait à tout prix les ériger en politique nationale pour les mourants. Nous voulons vraiment être reconnus parmi la communauté internationale pour ce que nous faisons pour les mourants.

L'Association catholique canadienne de la santé remercie encore une fois le Sénat d'avoir bien voulu l'entendre. Nous espérons que vous produirez un rapport bien senti. Si nous pouvons faire quoi que ce soit pour travailler avec vous à la mise en oeuvre de vos recommandations, nous serons heureux de le faire.

[Français]

**Mme Suzanne Vadboncoeur, directrice, Service de recherche et de législation, Barreau du Québec:** Il me fait plaisir d'être ici au nom du Barreau du Québec pour répondre à votre invitation concernant plus particulièrement du chapitre six du rapport sénatorial, c'est-à-dire les ententes et les directives préalables. Je suis accompagnée à ma gauche de Me Edith Deleury, professeure à l'Université Laval, à Québec, en droit de la famille, des personnes, et cetera, et qui fait partie de plusieurs comités d'éthique. À ma droite, Me Jean-Pierre Ménard est avocat de pratique privée, professeur et spécialiste en droit médical.

Nous sommes ici pour vous parler de la situation qui prévaut au Québec en matière de directives préalables. Je m'excuse tout de suite auprès des gens qui ne sont pas spécialistes du droit: notre exposé sera peut-être un petit peu plus technique que celui de l'association. J'espère néanmoins que nous vous mâcherons un peu l'exposé de façon à ce que ce soit assez compréhensible.

Au Québec, en matière de dispositions législatives ou réglementaires, voici ce qui guide autant les citoyens que les équipes médicales en matière de soins. Me Deleury vous parlera un petit peu plus du mandat en cas d'inaptitude, une création québécoise qui existe depuis 10 ans au Code civil, et Me Ménard vous parlera d'un véhicule très souple que l'on a avec le Code civil du Québec et qui est un petit peu plus large que le testament de vie.

We will conclude with two recommendations. In Quebec, legislative provisions with respect to care are governed by the Canadian Charter of Rights and Freedoms which, in section 7, states that everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice, and by the Quebec Charter of Human Rights which states in section 1 that every human being has a right to life, and to personal security, inviolability and freedom. He also possesses juridical personality.

These fundamental values, these fundamental rights form the basis of the new Quebec Civil Code which has been in force since January 1, 1994. The philosophy of the Civil Code focusses on the autonomy of the person, the rights and respect of his integrity, of his inviolability. The entire chapter on consent to care in the Civil Code is based on these fundamental values from the charter. In sections 10 and 11, the Civil Code reiterates the content of the charters. It establishes guidelines and basic principles that govern all provisions regarding consent to care. I am going to read section 10.

Every person is inviolable and is entitled to the integrity of his person.

Except in cases provided for by law, no one may interfere with his person without his free and enlightened consent.

That is the basis of everything. Section 11 states:

No person may be made to undergo care of any nature, whether for examination, specimen taking, removal of tissue, treatment or any other act, except with his consent.

If the person concerned is incapable of giving or refusing his consent to care, a person authorized by law or by mandate given in anticipation of his incapacity may do so in his place.

You can truly see that that is the fundamental basis of all provisions of the Civil Code.

Sections 12 to 25 of the Civil Code address consent to care. Whether it is a situation of being capable or incapable, real consent or substituted consent, cases of emergency or non-urgent situations, for care required according to the state of health or not, etc., there are provisions to cover all of these situations.

As for specific pieces of legislation, I must point out some that cover the delivery of care in Quebec. The Act respecting health services and social services — the Bible for doctors, nurses and hospitals — also sets out guidelines that must be used to manage and deliver health care and social services.

Once again, it revolves around the patient, around his right to integrity and his right to be informed of the care he is receiving. There is also the Public Curator Act which applies, namely in all cases where the person does not have a legal representative. In that case, the Public Curator acts as a tutor or curator and must, in

On terminera avec les deux recommandations. Au Québec, les dispositions législatives en matière de soins sont guidées par la Charte canadienne des droits et libertés qui, à son article 7, prévoit que chacun a droit à la vie, à la liberté et à la sécurité de sa personne, et qu'il ne peut être porté atteinte à ce droit qu'en conformité avec les principes de justice fondamentale et par la Charte québécoise des droits et libertés de la personne qui prévoit à son article 1 que tout être humain a droit à la vie, à la sûreté, à l'intégrité et à la liberté de sa personne. Elle possède également la personnalité juridique.

Ces valeurs fondamentales, ces droits fondamentaux sont à la base du nouveau Code civil du Québec qui est en vigueur depuis le 1<sup>er</sup> janvier 1994. Toute la philosophie du Code civil est axée sur l'autonomie de la personne, sur le droit et le respect de son intégrité, de son inviolabilité. Tout le chapitre du consentement aux soins dans le Code civil du Québec s'inspire de ces valeurs fondamentales inscrites dans la Charte. Le Code civil répète à ces articles 10 et 11 le contenu des chartes. Il pose les jalons et les principes de base qui guident toutes les autres dispositions en matière de consentement aux soins. Je vous fais lecture de l'article 10:

Toute personne est inviolable et a droit à son intégrité.

Sauf dans les cas prévus par la loi, nul ne peut lui porter atteinte sans son consentement libre et éclairé.

C'est la base de tout. L'article 11 dit:

Nul ne peut être soumis sans son consentement à des soins, quelle qu'en soit la nature, qu'il s'agisse d'examen, de prélèvements, de traitements ou de toute autre intervention.

Si l'intéressé est inapte à donner ou à refuser son consentement à des soins, une personne par la loi ou par un mandat donné en prévision de son inaptitude peut le remplacer.

On voit vraiment que c'est la base fondamentale de toutes les dispositions du Code civil.

Les articles 12 à 25 du Code civil parlent de consentement aux soins. Qu'on soit en situation de capacité ou d'incapacité, le consentement réel ou le consentement substitué, en cas d'urgence ou de non urgence, pour les soins requis selon l'état de santé ou non, et cetera, on a les dispositions qui couvrent toutes ces situations.

Quant aux lois particulières, certaines doivent être signalées ici en matière de prestations de soins au Québec. La Loi sur les services de santé et des services sociaux — la bible des médecins, des infirmières et des centres hospitaliers — énonce également les lignes directrices qui doivent servir à la gestion et à la prestation des soins et des services sociaux.

C'est encore une fois axé sur le patient, sur son droit à l'intégrité et son droit à être informé des soins qui lui sont dispensés. On a également la Loi sur le curateur public qui s'applique, notamment dans tous les cas où la personne n'a pas de représentant légal. Le curateur public agit à ce moment-là à titre



some cases, give his consent to the care that is being proposed for the person who is incapable of giving his own consent.

As for regulatory provisions governing care, there is the physicians' code of ethics. There are some sections that state that, once again, the physician must abstain from any action that is contrary to medical science data, and that he must only provide care or issue a prescription or prescribe treatment if medically necessary. Obviously, that is a criterion that must always be complied with when end-of-life care is being provided.

In the case of nurses, the code of ethics which must also be taken into consideration requires that nurses strive to establish a relationship of mutual trust with the patient, as well as respect the patient's values. We see here again that the desires expressed by the patient with respect to care or the interruption of treatment must normally be taken into account first and foremost.

That was a very quick overview of the legislative and regulatory provisions applicable in Quebec with respect to care, and I will now give the floor to Professor Edith Deleury so that she can tell you about the mandate in case of inability that is contained in the Quebec Civil Code.

**Ms Edith Deleury, Professor, Laval University:** I would like to thank you for the attention you are paying to the state of Quebec law in this area, and more specifically, in the area of advance directives. As Ms Vadboncoeur has already said, Quebec civil law has undergone a host of major reforms in recent years, and more specifically in the 1990s, when we reformed the safeguards for people who are incompetent and when we introduced the idea of a mandate in case of inability.

As its name indicates, the mandate in case of inability is a mandate, and it is part of the general provisions of legal acts governed by sections 21 and 30 of the Quebec Civil Code, from which it does however derogate with respect to specific provisions.

One of the features of the mandate, in the case of inability, is that it does not come into effect until the person has been found to be incapacitated. This mandate in case of inability allows us, when we are still fully lucid, to designate a person who, in the event of our becoming incapacitated, could take decisions on our behalf with respect to our treatment as a person and the administration of our property.

Under Quebec civil law, the mandate in case of inability is broader than the strict advanced directives for consent to care. This mandate in case of inability reflects, if you will, the spirit we referred to earlier and deals with respect for the autonomy of the person, which is the cornerstone for the Civil Code reform, and the basis for the previous reform of the rights of the legally incapacitated.

de tuteur ou de curateur et doit donc, dans certains cas, donner son consentement aux soins qui sont envisagés pour la personne inapte à donner son propre consentement.

Quant aux dispositions réglementaires qui entourent la prestation des soins, vous avez le code de déontologie des médecins. Il y a certains articles qui énoncent que, encore une fois, le médecin doit s'abstenir de faire des actes contraires aux données de la science médicale, et qu'il ne doit fournir un soin ou donner une ordonnance de médicaments ou de traitements que si ceux-ci sont médicalement nécessaires. Évidemment, c'est un critère qui devra être toujours présent lors de soins donnés à l'approche de la mort.

Dans le cas des infirmiers et des infirmières, le code de déontologie, qui doit être également pris en considération, exige des infirmiers et infirmières la recherche de l'établissement d'une relation de confiance mutuelle avec le patient, ainsi que le respect des valeurs de celui-ci. Nous voyons encore une fois que la volonté exprimée par le patient, quant aux soins ou à l'interruption des traitements, doit normalement être prise en considération au premier chef.

Ceci était un survol très rapide des dispositions législatives et réglementaires applicables au Québec en matière de soins, et je cède maintenant la parole au professeur Edith Deleury, afin qu'elle vous expose le mandat en cas d'incapacité du Code civil du Québec.

**Mme Edith Deleury, professeure, Université Laval:** Merci à l'auditoire de l'attention qu'ils veulent bien nous apporter concernant l'état du droit québécois en la matière et, plus particulièrement, en matière de directives préalables. Comme Me Vadboncoeur vous l'a exposé, le droit civil québécois a connu un vent de réformes important au cours des dernières années, et particulièrement dans les années 90, lorsqu'on a réformé les régimes de protection des majeurs inaptes et qu'on a introduit cette notion de mandat en cas d'incapacité.

Le mandat en cas d'incapacité, comme son nom l'indique, est un mandat et il s'inscrit dans les dispositions plus générales des actes juridiques régis par les articles 21 et 30 du Code civil du Québec, auquel il vient cependant déroger en ce qui a trait à des dispositions particulières.

Le mandat a la particularité, en cas d'incapacité, de ne prendre effet qu'une fois la personne déclarée inapte. Ce mandat d'incapacité permet, alors que nous sommes encore en pleine possession de nos moyens, de désigner la personne qui, advenant l'hypothèse ou nous deviendrions inaptes, pourrait prendre des décisions en notre nom, lieu et place, à la fois quant au gouvernement de notre personne et quant à l'administration de nos biens.

Le mandat en cas d'incapacité, dans le cas du droit civil québécois, a donc une dimension plus large que les strictes directives préalables relatives au consentement aux soins. Ce mandat en cas d'incapacité reflète en quelque sorte l'esprit dont on a fait mention tout à l'heure et qui concerne le respect de l'autonomie de la personne, qui est la pierre angulaire sur laquelle a été bâtie la réforme du Code civil, et sur laquelle avait été bâtie préalablement cette réforme du droit des incapables majeurs.



Of course this mandate must be approved before coming into effect. This approval presupposes that the person's incapacity has been verified. It enables a person to set out what care he wants to receive or not, to clearly outline it, and to place decision-making power in the hands of a third party.

So we are talking about a representative that the person designates himself, to whom he entrusts the responsibility of making decisions in accordance with his wishes as expressed. The mandate in case of inability is a document that has increased in use since 1990, and especially since 1994.

Here are some figures: in total, between 1990 — when these provisions came into force — and 1998, 7,904 mandates were approved. These are impressive figures that increase statistically on an annual basis. Another interesting fact to note is that on June 30, 1996, there were almost 400,000 notarized registered mandates, in other words, mandates that had not yet been approved. That is without counting the ones on the Bar's registration list and the mandates that have not been registered by one of the two chambers.

This mandate generally includes clauses covering the refusal of aggressive treatment and also what is referred to as a living will. However, as I pointed out earlier, the mandate can sometimes be limited to simply administering the person and sometimes to the simple administration of his property, in which case it can be completed with protective supervision.

The idea is to enable the person to equip himself with protective supervision that is strictly private. He determines his own protective supervision, which will entrust his mandatar with the responsibility, in accordance with the directives provided, of making decisions that will be taken regarding consent to care.

It is true that the mandate has its limits, and we have listed some of them in our brief. The first of these limits is that the mandate represents the will of the mandator at a specific point in time, in other words when the mandator drafted the mandate, whereas consent to care, as we know, is an on-going and evolving process by definition.

The sometimes vague nature of its wording can give rise to ambiguity and leave room for interpretation. There are in fact mandates that can be written in general terms. When someone says that he does not want extraordinary care to be administered to him, the word "extraordinary", as we know, gives rise to many discussions. There is a tendency to replace this terminology with "care that is not disproportionate with respect to the state of the person", which is much more accurate.

Nevertheless, the way the mandator drafts the mandate is extremely important with respect to the way that the mandatar will apply it. In this regard, perhaps a public education and information process should be put in place.

Ce mandat doit bien sûr faire l'objet d'une homologation pour pouvoir prendre effet. Une homologation qui suppose que l'on ait pu vérifier la survenance de l'incapacité de la personne. Cela permet à une personne d'exprimer les soins qu'elle voudrait recevoir ou non, d'en faire état, et de confier les décisions qui devront être prises à son endroit à une tierce personne.

Il s'agit donc d'un représentant que la personne désigne elle-même, à qui elle confie le soin de prendre les décisions conformément aux volontés qu'elle aura pu exprimer. Le mandat en cas d'incapacité est un document de plus en plus utilisé depuis 1990, et particulièrement depuis 1994.

Voici quelques chiffres : au total, entre 1990 — date d'entrée en vigueur de ces dispositions — et 1998, il y a eu 7904 mandats qui ont été homologués. Ce sont des chiffres impressionnants qui, annuellement, augmentent statistiquement. Un autre fait intéressant à noter est qu'au 30 juin 1996, il y avait presque 400 000 mandats notariés enregistrés, c'est-à-dire des mandats qui n'ont pas encore été homologués. Sans compter ceux qu'on peut retrouver au registre d'inscription du barreau et des mandats qui n'auraient pas fait l'objet d'un enregistrement auprès de l'une ou l'autre des deux chambres.

Ce mandat englobe généralement des clauses de refus d'acharnement thérapeutique et aussi ce qu'on appelle le testament biologique. Cependant, comme je l'ai souligné tout à l'heure, le mandat peut parfois se limiter à la simple administration de la personne et peut parfois se limiter à la simple administration des biens, auquel cas il pourrait être complété par l'ouverture d'un régime de protection.

L'idée est de permettre à la personne de se doter elle-même d'un régime de protection strictement privé. C'est elle qui organise son régime de protection, qui va confier à son mandataire le soin, selon les directives qui lui ont été données, des décisions qui devront être prises relativement au consentement aux soins.

Il est vrai que le mandat a ses limites et on en a énumérées un certain nombre dans notre mémoire. La première de ces limites est qu'il représente la volonté du mandant à un moment précis, c'est-à-dire le moment où le mandant a rédigé le mandat, alors que le consentement aux soins, on le sait, est un processus continu et évolutif par définition.

Le caractère parfois un peu vague de sa formulation peut soulever des ambiguïtés et laisser place à l'interprétation. Il y a effectivement des mandats qui peuvent être formulés en termes généraux. Quand on dit ne pas vouloir qu'on nous administre des soins extraordinaires, le mot «extraordinaire», on le sait, a donné lieu à de nombreuses discussions. On note une tendance à remplacer cette terminologie par «soins qui ne soient pas disproportionnés par rapport à l'état de la personne», ce qui est beaucoup plus exact.

Il reste que la façon dont le mandant rédige le mandat est extrêmement importante par rapport à l'application que va en faire le mandataire. À ce sujet, il y a peut-être un processus d'éducation à mettre en place et de l'information à véhiculer auprès des personnes.

Since it is also a written document, it is an instrument that is less flexible than a verbal expression of one's wishes. Moreover, the health care team may be unaware of the existence of the mandate, the mandator or the mandataire as they may not always have the document at their fingertips, especially in the event of an emergency.

This document is also somewhat formal, since it must be approved. It is true that the legislator added some flexibility about two years ago, since it is now possible for a notary to proceed with the instruction and follow up the request for approval before the courts, but it is still the court that will make the decision as a last resort.

Moreover, contrary to provisions governing protective supervision of persons of full age who are unable to give consent which were put in place by the Quebec legislators in the 1990s, with this mandate, it is impossible to restrict the powers of the representative that have been designated by the person, based on the person's degree of incapacity.

The mandataire, once the mandate has been approved, has full powers with respect to treatment of the person, and moreover, based on the interpretation set out in section 21.35, paragraph 2 of the Civil Code, with the exception of specific provisions, he is entrusted with full authority over administration, even if the person is only partially incapacitated.

So it is impossible to make changes based on the degree of the person's incapacity. Whereas under protective supervision, such as tutorship or curatorship, respect for the residual autonomy is a factor that must be taken into account by the court that must decide whether or not to use protective supervision.

Finally, with respect to carrying out the mandate, there is no monitoring mechanism. The only possibility that exists is requesting that the mandate be revoked.

This instrument does have its limits, but as we have seen, it has made great strides since it was introduced in the Quebec Civil Code. It is complemented by provisions in section 12 with respect to substituted consent, to which it is linked and on which I will let Mr. Ménard continue.

**Mr. Jean-Pierre Ménard, Barreau du Québec:** We will start with section 12 of the Civil Code which is a mechanism for expressing one's wishes that is a bit broader than the mandate and much less formal, and which oddly enough, was overlooked in the 1995 report. When looking at chapter 6, under administrative directives, we realized that the report is silent on section 12 of the Civil Code which offers an approach that is much broader, less formal and easier to use than the mandate or the other mechanisms for expressing one's wills that have been discussed to date.

It is interesting to examine section 12, because in introducing this mechanism, the Quebec legislator decided to take a path that is considerably different from common law rules. Section 12 of the Quebec Civil Code is an original creation of Quebec civil law with respect to advanced directives. It is important to look at how

Comme il s'agit également d'un écrit, c'est un instrument qui est moins flexible que l'expression verbale de la volonté. Par ailleurs, l'équipe soignante peut parfois ignorer l'existence du mandat, le mandant ou le mandataire n'ayant pas toujours le document à portée de la main, particulièrement lorsqu'on fait face à une situation d'urgence.

C'est aussi un acte qui est empreint d'un certain formalisme, puisqu'il faut faire homologuer le mandat. Il est vrai qu'il y a eu un certain assouplissement qui a été apporté par le législateur il y a presque deux ans, puisqu'il y a maintenant la possibilité de charger un notaire de procéder à l'instruction et faire suivre la demande d'homologation devant le tribunal, mais c'est toujours le tribunal qui prend la décision en dernier ressort.

Par ailleurs, contrairement aux régimes de protection des majeurs inaptes qui ont été mis en place par le législateur québécois dans les années 90, il est impossible dans le cadre du mandat, de pouvoir baliser les pouvoirs du représentant qui aura été désigné par la personne, en fonction du degré d'incapacité de cette personne.

Le mandataire, une fois le mandat homologué, a en ce qui a trait au gouvernement de la personne, pleins pouvoirs, et par ailleurs, selon l'interprétation qui a été donnée à l'article 21.35, alinéa 2 du Code civil, il se voit confié, sauf dispositions spécifiques, les pleins pouvoirs d'administration, même si l'incapacité de la personne n'est que partielle.

Il n'y a donc pas de possibilité de modulation en fonction du degré d'incapacité de la personne. Alors que dans le cadre des régimes de protection, tels la tutelle ou la curatelle, le respect de l'autonomie résiduelle est un facteur qui doit être pris en compte par le tribunal qui doit décider de l'ouverture ou non d'un régime de protection.

Enfin, par rapport à l'exécution du mandat, il n'y a aucun mécanisme de surveillance. La seule possibilité qui peut s'offrir, c'est de demander la révocation du mandat.

Cet instrument a ses limites, mais on le voit, il a fait de grands pas depuis son introduction dans le Code civil du Québec. Il est complété par les dispositions de l'article 12 relatives au consentement substitué, avec lesquelles il s'articule et sur lesquelles je laisserai Me Ménard poursuivre.

**M. Jean-Pierre Ménard, Barreau du Québec:** Nous allons aborder l'article 12 du Code civil qui est un mécanisme d'expression de volonté un peu plus large que le mandat et beaucoup moins formaliste et qui, de façon bien curieuse, a échappé au rédacteur du rapport en 1995. Lorsqu'on regarde le chapitre 6, sous les directives préalables, on se rend compte que le rapport est silencieux sur l'article 12 du Code civil qui offre pourtant un moyen beaucoup plus large, beaucoup moins formaliste et plus facile d'exercice que le mandat ou que les autres mécanismes d'expression de volonté dont on a parlé jusqu'à maintenant.

Il est intéressant de regarder cet article 12 parce que le législateur québécois a décidé, lorsqu'on a introduit ce mécanisme, de suivre une voie qui est substantiellement différente des règles de la common law. L'article 12 du Code civil du Québec est une création originale du droit civil du Québec par



it is different from the path chosen by common law to discuss these issues.

Our common law rules are strongly based on the evolution of American law in this area. Following a series of decisions by the U.S. Supreme Court in the *Quinlan* case, which challenged the State's interests in preserving life, in opposition to the wishes expressed by the person who was dying, the United States Supreme Court adopted the following approach: when a person has not issued directives or expressed his will with respect to his end-of-life conditions, the State must step in and the State must essentially act with a view to protecting and maintaining life. That is the philosophy of the role of the State with respect to maintaining life in a common law system; the same holds true for rules governing abortion and end-of-life decisions.

The State has a preponderant role to play in preserving and sustaining life. The Supreme Court has said that, where the patient has not given any instructions, the State has the duty to sustain life. And so, States have legislated to that effect. There are over 10,000 brain-dead patients in hospital in the United States who are on very costly life support without any real hope of improvement in their condition.

Almost all jurisdictions in the United States have established rules with respect to living wills. They have set conditions under which patients can express their end-of-life wishes. These conditions are generally quite prescriptive and subject to the existence of medical prognoses, as well as specific term and formats. The trend in many Canadian provinces is to pass similar legislation, or legislation modeled after these rules.

However, Quebec's Civil Code has an entirely different approach, which is much broader and which does not flow from the principles of American common law, but which essentially draws from the Civil Code philosophy with respect to personal autonomy. You will find this on page 7 of our brief. It says that a person who gives his consent to or refuses care for another person is bound to act in the sole interest of that person, taking into account, as far as possible, any wishes the latter may have expressed. That is a key element of section 12 of the Civil Code.

It goes on to say that if he gives his consent, he shall ensure that the care is beneficial notwithstanding the gravity and permanence of certain of its effects, that it is advisable in the circumstances and that the risks incurred are not disproportionate to the anticipated benefit.

How is this different from the legal framework that is to be found in the advanced directives? There are several differences. The wishes may be expressed at any time when a decision must be made, so that there is no rigidity. There is no time limit. It is possible that the wishes could have been expressed 5, 10 or 15 years earlier. The issue is whether or not these wishes are still valid. There is no formal procedure as such. There is no need for the courts to be involved or to confirm the wishes. These can be expressed at any time. It is very flexible. A decision can be

rapport aux directives préalables. Il est important de regarder en quoi cela s'écarte du chemin choisi par la common law pour parler de ces choses.

Nos règles de common law sont fortement inspirées par l'évolution du droit américain à ce sujet. Suite à une série de décisions de la Cour suprême des États-Unis dans les affaires de *Quinlan*, où on mettait en cause l'intérêt de l'État à préserver la vie, par opposition aux volontés exprimées par la personne qui se trouvait en fin de vie, la Cour suprême des États-Unis a privilégié l'approche suivante: lorsqu'une personne n'a pas émis de directives ou de volontés par rapport à ses conditions de fin de vie, l'État se devait d'intervenir et l'État devait agir essentiellement dans l'optique de la protection du maintien de la vie. C'est toute la philosophie du rôle de l'État par rapport au maintien de la vie dans le système de common law, autant en matière de règles concernant l'avortement qu'en matière de décisions de fin de vie.

L'État a un rôle prépondérant pour assurer la préservation et le maintien de la vie. La Cour suprême dit que dans la mesure où on n'a pas de directives de la personne, l'État doit assurer le maintien de la vie. Les États ont donc légiféré. On a plus de 10 000 patients dans les hôpitaux aux États-Unis à un stade neuro-végétatif qui doivent être maintenus en vie de façon très coûteuse et sans espoir sérieux d'améliorer leur sort.

Les États-Unis ont légiféré, à peu près toutes les juridictions, pour mettre en place des règles pour le testament biologique. Ils ont prévu des conditions d'expression des volontés de fin de vie. Ces conditions sont en général assez formalistes et assujetties à l'existence de pronostics médicaux, à une limite quant à leur durée et à leur forme. On tend à adopter, dans plusieurs provinces du Canada, des législations qui se ressemblent ou qui sont inspirées de ces règles.

Le Code civil du Québec a choisi une approche tout à fait différente, beaucoup plus large et qui ne s'inspire pas des principes de la common law américaine, mais qui s'inspire essentiellement de la philosophie du Code civil par rapport à l'autonomie des personnes. Vous avez une description à la page 7 du mémoire. On dit que celui qui consent à des soins pour autrui ou qui les refuse est tenu d'agir dans le seul intérêt de cette personne en tenant compte, dans la mesure du possible, et c'est ici la disposition importante, des volontés que cette dernière a pu manifester. C'est l'élément clé de l'article 12 du Code civil.

On y dit que s'il exprime un consentement, il doit s'assurer que les soins seront bénéfiques malgré la gravité et la permanence de certains de leurs effets, qu'ils sont opportuns dans les circonstances et que les risques présentés ne sont pas hors de proportion avec les bienfaits qu'on en espère.

Quelle est la différence par rapport à l'encadrement juridique qu'on trouve relativement aux directives préalables? Il y en a plusieurs. Cela peut être exprimé à n'importe quel moment où il faut prendre ces décisions, donc il n'y a aucun formalisme. Il n'y a pas de limite de temps. Ces volontés peuvent avoir été exprimées il y a 5, 10 ou 15 ans. Le tout est de savoir si ces volontés sont toujours actuelles. Il n'y a pas de cadre de procédure. Cela n'est pas assujéti à une quelconque intervention ou vérification du tribunal, ce sont des questions de fait



made today, just as it can be made tomorrow. The wishes can be expressed either orally or in writing. The individual can then change his or her mind very quickly in response to changing circumstances. This is then a very flexible vehicle which has a much broader scope than a mandate given in case of incompetency, which is one of the means by which a person can express his or her wishes, but it much broader than that. It very simple and easy to use.

However, its simplicity does limit what can be done. It can sometimes be difficult to prove that these are indeed the previously expressed wishes of the patient. The medical community tends to always seek a certain level of certainty or guarantee in assessing these decisions, especially when they are quite significant and far-reaching. Often, they will question the validity of the patient's wishes in the absence of any real evidence. That is perhaps one of the shortcomings of this mechanism.

The mechanism is much broader than the rules of common law with respect to living wills and other such vehicles. If what you are looking for in this debate — and this is important for your committee — is some standardization or interprovincial agreement on these things, the Barreau du Québec would say to you: do be careful. Given that the Civil Code rules are broader, more permissive, and more centered on personal autonomy than those of other provinces, the Barreau du Québec is rightly concerned that the scope of section 12 of the Civil Code might be decreased if the goal is to have standardized principles for all provinces at any cost.

It is important that principles found exclusively in the Civil Code can apply to any situation where a Quebecker under these regulations must make an end-of-life decision. The mechanism in section 12 is original and inspired by the Civil Code. It is somewhat different from, though there are some meeting points between the two, the thinking followed in common law. It is inspired purely by the Civil Code and it is important for the Barreau du Québec that its workings be clear in any type of intervention to be made concerning a person's last wishes.

[English]

**Senator Beaudoin:** I am very impressed by the testimony we have heard this morning. It is fascinating.

[Translation]

I asked this question to Dr. Lamontagne the other day. I asked him: Do you believe that we need to legislate or not?

I have listened to the common law and civil law experts this morning. Of course, there are many pieces of legislation in Quebec and in the other provinces.

If we leave aside the terms "euthanasia" and "assisted suicide", what we agree to unanimously in our report is that we must legislate in certain areas such as the unhooking of life-support machines, refusal of treatment and aggressive therapy.

momentanées, cela est très flexible. Cela peut se décider aujourd'hui ou demain. Ces volontés peuvent être exprimées verbalement ou par écrit. Dans cette matière, l'opinion de la personne peut changer très rapidement par rapport aux situations auxquelles elle fait face. C'est donc un véhicule très flexible, de portée beaucoup plus large qu'un mandat d'incapacité, dont le mandat est un des moyens où on peut retrouver l'expression de la volonté des personnes, mais c'est beaucoup plus large. C'est extrêmement simple et facile d'exécution.

Cette simplicité comporte aussi des limites. Il peut parfois être difficile de faire la preuve de ces volontés exprimées antérieurement. Le milieu médical va toujours rechercher une certaine certitude ou sécurité par rapport à l'évaluation de ces décisions, surtout si elles sont conséquentes et importantes. Il va chercher souvent à questionner le bien-fondé de ces volontés si on n'en a pas une preuve quelconque. C'est peut-être la limite de ce mécanisme.

Ce mécanisme est beaucoup plus large que les règles de la common law par rapport au testament biologique et aux autres mécanismes du genre. Dans ce contexte, si on parle de chercher — c'est important pour votre comité — une certaine uniformisation ou d'entente inter-provinciale par rapport à ces choses, le Barreau du Québec vous dit: attention, tenant compte que les règles du Code civil sont plus larges, plus permissives et plus orientées en fonction de l'autonomie de la personne que celles des autres provinces, le Barreau du Québec craint bien légitimement de voir la portée de l'article 12 du Code civil réduite, si on veut à tout prix uniformiser les principes d'une province à l'autre.

Il est important que les principes propres au Code civil puissent s'exprimer dans toute situation où un Québécois régit par ces règles se retrouve en décision de fin de vie. Le mécanisme de l'article 12 est original et d'inspiration civiliste. Il s'écarte un petit peu, bien qu'on se rejoigne à un certain stade, du mécanisme de production de cette réflexion si on veut, du cheminement suivi par la common law. Il est d'inspiration purement civiliste et il est important pour le Barreau du Québec que l'économie de cette règle soit claire, dans toute forme d'intervention que l'on décidera de faire par rapport aux volontés de fin de vie.

[Traduction]

**Le sénateur Beaudoin:** J'ai trouvé les témoignages de ce matin très intéressants, très instructifs.

[Français]

J'ai posé l'autre jour la question au docteur Lamontagne. Ma question était la suivante: pensez-vous que nous avons besoin de légiférer ou non?

J'ai écouté les gens du common law et ceux du droit civil ce matin. Évidemment, nous avons beaucoup de dispositions législatives, tant au Québec que dans les autres provinces.

Ce sur quoi nous sommes unanimes dans notre rapport, si nous écartons les termes «euthanasie» et «suicide assisté», c'est qu'il faut légiférer sur certains domaines tels le débranchement d'appareils, le refus de traitement et l'acharnement thérapeutique.

I believe that we need to improve our Criminal Code. However, I would like to know what you think. Maybe you will tell me that the Civil Code is a extremely good document. I am sorry that we did not mention section 12. That was a mistake, but let us not forget that it came at the very end of the report in 1995.

Is this legislation enough? Should we legislate? I believe that we should do so, at least to amend the Criminal Code as the civil law seems very solid to me. Mr. Ménard emphasized the difference between the common law and the civil law: one is written and the other one is based on precedents.

**Ms Deleury:** The Barreau du Québec underlined in its brief that it seems timely to amend the Criminal Code as you suggested yourself in your report in 1995. I refer especially to page 34 of the report.

These amendments would clarify matters for practitioners and this might bring about a lowering of the current resistance as we still see defensive medicine.

**Senator Beaudoin:** Is your answer yes?

**Ms Deleury:** For my part, yes, and I believe that it is also the opinion of the Barreau du Québec. The Criminal Code needs to be clarified. The Law Reform Commission of Canada itself suggested it and there seemed to be some consensus about it.

As for the Civil Code, its provisions are sufficiently flexible and it is true that they are not perfect. They have been shown to have their limits, but I believe that they work well together and can be applied to most situations.

We find certain medical and hospital cultures in certain circles. People tend to be afraid of being sued, which can lead them to taking more aggressive action in the fear that palliative care might be considered a criminal action under the Criminal Code.

[English]

**Dr. Latimer:** I am a clinician. I have been in this field for 18 years. I do not think physicians on the clinical level are worried about legal liability for certain kinds of treatment. I come back to the issue of clinical services and education. If anything, the sorts of educational recommendations that we are making would mean that all health care team members would know about these things — that is, cessation of treatment, advance directives, et cetera. If anything — and, again, this is my impression — I think the concept of people being over-treated is actually not true. Health care has moved along in such a way that if a person indicates that they want to cease treatment and, accordingly, have given a sense of that either to their families or via a directive, I believe that their health care teams and their doctors are quite willing to embrace that. In fact, it may be more difficult, as a result some of the recent downsizing of our health care delivery

Je pense qu'il faut améliorer notre Code criminel. J'aimerais toutefois savoir quelle est votre opinion; peut-être me direz-vous que le Code civil est fort bien fait. Quant à l'article 12, je regrette qu'on n'en ait pas parlé. C'est une erreur, mais n'oublions pas que c'était à la toute fin du rapport, en 1995.

Est-ce que cette législation suffit? Devons-nous légiférer? Je pense qu'il faut le faire, au moins pour le Code criminel puisque le droit civil m'apparaît très solide. M. Ménard a souligné la différence entre la common law et le droit civil; l'un est écrit, l'autre est un droit basé sur les précédents.

**Mme Deleury:** Le Barreau du Québec a souligné dans son mémoire qu'il semblait être opportun, effectivement, que l'on puisse apporter des modifications au Code criminel, dans le sens où vous l'avez vous-même proposé dans le rapport que vous avez déposé en 1995. Je fais référence plus particulièrement à la page 34 de votre document.

Ces modifications clarifieraient les choses pour les praticiens et on verrait peut-être moins de résistance qu'on en voit actuellement, alors que l'on constate qu'il y a encore une forme de médecine défensive qui se pratique.

**Le sénateur Beaudoin:** Est-ce que votre réponse est oui?

**Mme Deleury:** Personnellement, oui, et je pense que c'est également l'opinion du Barreau du Québec. Il faudrait effectivement clarifier le Code criminel. La Commission de réforme du droit du Canada l'a elle-même proposé et un certain consensus semblait se dégager à cet effet.

En ce qui concerne le Code civil, nous avons des dispositions suffisamment souples, et il est vrai qu'elles ne sont pas parfaites. On a démontré que ces dispositions ont leurs limites, mais je pense qu'elles se conjuguent et permettent de faire face à la plupart des situations.

Dans certains milieux, il y a des cultures médicales et hospitalières. Il y a aussi cette tendance à avoir peur de la poursuite, ce qui fait qu'on peut se montrer plus agressif, de peur que l'administration de soins palliatifs ne soit considérée, au sens du Code criminel, comme une infraction.

[Traduction]

**Dre Latimer:** Je suis clinicienne. Je suis dans le métier depuis 18 ans. Je ne pense pas que les médecins cliniciens s'inquiètent des responsabilités juridiques de certaines formes de traitement. Je reviens à la question des services cliniques et de l'éducation. Au minimum, le genre de recommandations éducatives que nous faisons signifierait que tous les membres des équipes de soins seraient au courant de ces questions — à savoir, des questions de cessation de traitement, de directives préalables, et cetera. Je crois, et encore une fois, c'est mon impression personnelle, que cette notion d'acharnement thérapeutique est une vue de l'esprit. La notion de soins a évolué de telle manière que si un patient réclame une cessation de traitement et qu'il a instruit au préalable sa famille et qu'il a donné des directives dans ce sens, je crois que le médecin et l'équipe qui le soignent sont tout à fait disposés à accéder à cette requête. En fait, certaines des récentes



system, to get aggressive life-support treatment than to have treatment cease.

That may be a new idea for the committee. I do not know if you have heard that from anyone else. Cessation of treatment occurs when there is a wish on the part of the patient or family agreement — that is, not a divisive situation. Where the clinical context is correct, I think many clinicians and doctors are opening to those sorts of directives, either verbal or written. However, the patient who wants to find life support beyond what a physician would find reasonable may have a more difficult time receiving that sort of care.

I do not know whether legislation is the answer. I believe education is the answer. We have proposed main stream educational recommendations that, as of next year, all medical schools should have palliative care and end-of-life care, including the legalities, in their curriculum. It would please me tremendously if that recommendation were made.

[Translation]

**Mr. Ménard:** There is a major difference between the legislation we have and how it is applied. We need to have rules to make society feel safer. The problem we now have is that even with the rules we do have, we find that there is quite a difference between the legislation as it is expressed and understood here and the way it is applied every day in night hospitals and long-term care facilities.

Even if we wanted to work on the legislation, we would need to provide education for society. The families, patients, medical practitioners and academics have to be informed about these rules.

These are not rules in the sense of clauses, but principles. Essentially, the law contains principles and these principles must be well known, because the implementation issues with these laws arise because people either ignore them, do not understand them or are afraid of these rules.

You can have all the legislation in the world, the problem is, if it is not understood, if it is not applied, and if it does not frame the whole decision-making process, then we will be back here in ten years' time discussing these principles and trying to understand why they were not applied.

I think that what Dr. Latimer underlined is very important. The issues are different depending on the care environment. It is true that more and more, the real concern of elderly and vulnerable people is not being over-treated, it is a concern of not being treated enough.

There is a growing problem, which legally, will create some major challenges in access to care and in access to some specific forms of care. In the health care sector there is a growing reluctance — unfortunately — to restrict access to certain levels of care on the basis of age, for example, and not on the basis of medical prognoses, which is quite different.

compressions de personnel et de ressources dans le domaine de la santé rendent plus probable, je crois, la cessation de traitement que l'acharnement thérapeutique.

C'est peut-être nouveau pour vous. Vous n'en avez peut-être pas entendu parler jusqu'à présent. Il y a cessation de traitement quand il y a souhait du patient ou accord de la famille — c'est-à-dire, unanimité. Lorsque le contexte clinique est correct, je crois que nombre de cliniciens et de médecins sont prêts à accepter ce genre de directives, qu'elles soient orales ou écrites. Par contre, il est possible que le patient qui réclame des moyens de survie au-delà de ce que le médecin considère raisonnable rencontre plus de difficultés à les obtenir.

Je ne sais si la loi peut apporter une réponse. Je crois que l'éducation peut l'apporter. Nous recommandons d'une manière globale qu'à compter de l'année prochaine, toutes les écoles de médecine enseignent les soins palliatifs et les soins de fin de vie et y incluent les questions juridiques. J'espérerais un immense plaisir si ce genre de recommandation était faite.

[Français]

**M. Ménard:** Il existe un écart important entre la législation telle qu'on l'a et telle qu'on l'applique. Il est nécessaire, pour sécuriser la société, d'adopter des règles ici et là. Mais le problème qu'on a actuellement, c'est que même par rapport aux règles qu'on a, on se rend compte qu'il y a un fossé important entre la loi, telle qu'on va l'exprimer et la comprendre ici, et lorsqu'on en arrive au quotidien, dans les centres d'hébergement et de soins de longue durée, par rapport aux personnes.

Même si on veut développer la législation, il faudrait travailler au niveau de la société à des mesures d'éducation. Il faut informer les familles, les patients, le milieu médical, les milieux académiques de ces règles.

Ce ne sont pas des règles en termes d'articles, mais des principes. Dans le fond, ce sont des principes que l'on retrouve à travers la loi et ces principes doivent être bien connus parce que la mise en œuvre de ces lois se pose essentiellement parce qu'on a affaire à des gens qui les ignorent, qui les comprennent mal ou à qui ces règles font peur.

Même si on veut de la législation et encore de la législation, le problème est que si elle n'est pas comprise, pas appliquée, et si elle n'imprègne pas les processus de décision, on va encore être ici dans dix ans à discuter de ces beaux principes pour essayer de comprendre pourquoi on ne les a pas appliqués.

Je pense que ce que le docteur Latimer souligne est fort important. La problématique change par rapport à l'environnement dans lequel les soins sont donnés. Il est vrai que de plus en plus, la grande crainte des personnes âgées et des personnes vulnérables n'est pas d'être surtraitées, c'est de n'être pas assez traitées.

Il existe une problématique qui se développe et qui est croissante, qui, juridiquement, va poser des défis fort importants d'accès aux soins et d'accès à certains soins en particulier. Il existe dans le milieu de prestation des soins de santé une certaine réserve qui croît avec l'usage — malheureusement — de restreindre l'accès à certains niveaux de soins en fonction de



In an emergency, the first question that is asked is "How old are you?" This may determine treatment, in part, and this should never be accepted. Legislators need to send a clear message. Access to services must never be determined by age, care should really be determined by the medical prognosis of each individual.

This is a growing issue, even more so than the issue of suspending treatment. Whether or not decisions are being made for that person, it is access to certain forms of care that will extend their life. This issue is going to grow exponentially before long.

**Senator Pépin:** Doctor Latimer, you say that physicians do not seem to fear a backlash. However we have heard otherwise. It probably depends on the province. It has been said that some physicians or that some nurses fear a backlash if they provide the palliative care proposed. This is what we have been told, that even if the will is there, they are afraid of implementing it. Yet you say no?

[English]

**Dr. Latimer:** I do not have a sense that that is the case, no. I think there may be some confusion about how best to treat patients sometimes, and I believe that that is an educational need, an education need in terms of how much analgesic, what are the goals of care, how to help a sick person and their family make decisions at end of life for palliative care. There may be confusion around how to proceed with all that, but with the exception of complex situations, which do arise now and again in any institution, health care hospital or at home, such as a family divided, et cetera, or other kinds of issues, it is my sense that most physicians and health care team members wish to do the best for the patient. They need guidance, advice and some teaching in how to do that. They also need the presence of an interdisciplinary health palliative care team in their setting upon whom they can call.

In some of the more high-profile problematic cases we have seen in Canada, I am not sure whether those teams were available or were accessed to assist with care. However, I do not hear people saying that they are worried about repercussions if the process is followed, if there is good dialogue with the family, with the patient, if there is good symptom control, good documentation of what is done, the nature of the symptoms, why medications have been applied, and the results of that application.

**Senator Pépin:** The difference is between the process and how it is organized.

**Dr. Latimer:** Health care delivery systems are grossly inadequate in this way. It is as though, in educating undergraduate students, from that beginning, we do not acknowledge that 50 per cent of the people for whom doctors and nurses care will

l'âge, par exemple, et non pas en fonction du pronostic médical, ce qui est bien différent.

La première question qu'on demande à quelqu'un dans une urgence: «Quel âge avez-vous?» Cela peut déterminer une partie de la conduite qu'on aura, alors qu'on ne devrait jamais accepter cela. Il faut qu'au niveau du législateur, on lance un message bien clair. L'âge ne devrait jamais conditionner l'accès aux services, c'est vraiment le pronostic médical propre à chaque individu qui devrait conditionner ces choses.

On a une difficulté qui est croissante, plus encore que les questions d'interruption de traitements. Décider pour la personne ou non, c'est l'accès à certains soins qui vont prolonger la vie des personnes. Cette problématique va prendre une importance exponentielle d'ici peu.

**Le sénateur Pépin:** Docteur Latimer, vous nous dites que les médecins ne semblent pas craindre des représailles. On a cependant eu des représentations à cet effet. Cela dépend probablement des provinces. On nous dit que certains médecins ou certaines infirmières craignent des représailles s'ils donnent des soins palliatifs tels qu'indiqués. On nous a expliqué cela en disant que même si la volonté est là, ils ont peur de l'appliquer. Vous nous dites que non?

[Traduction]

**Dre Latimer:** Ce n'est pas mon impression, non. Je crois qu'il y a peut-être une certaine confusion quant à la meilleure manière de traiter les patients, parfois, et je crois qu'il y a un besoin éducatif. Il faut que les professionnels de la santé comprennent les analgésiques, les objectifs de la santé, apprennent comment aider les malades et leurs familles à prendre certaines décisions relativement aux soins palliatifs de fin de vie. Toutes ces questions créent peut-être une certaine confusion, mais à l'exception de situations complexes qui surviennent de temps à autre dans tout établissement, tout hôpital ou à domicile, parce qu'il y a division au sein de la famille, et cetera, ou d'autres problèmes, j'ai l'impression que la majorité des médecins et des membres des équipes de soins souhaitent faire de leur mieux pour leurs patients. Ils ont besoin d'être guidés, ils ont besoin de conseils et d'enseignement sur cette question. Ils ont également besoin, dans leur lieu de travail, de la présence d'une équipe de soins palliatifs multidisciplinaire à laquelle ils peuvent faire appel.

Dans certains des cas qui ont connu le plus de publicité au Canada, je ne suis pas certaine que ce genre d'équipe ait été disponible ou qu'on y ait fait appel. Par contre, je n'entends personne s'inquiéter de représailles si la procédure est suivie correctement, si le dialogue est bien engagé avec la famille, avec le patient, s'il y a un bon contrôle des symptômes, une bonne documentation sur ce qui est fait, la nature des symptômes, la raison de l'application de certaines médicaments et les résultats de cette application.

**Le sénateur Pépin:** La différence est entre la procédure et son application.

**Dre Latimer:** Il y a une énorme carence de prestation de soins de santé à ce niveau. On a l'impression qu'on ne dit jamais aux étudiants, dès le départ, que 50 p. 100 des patients dont ils s'occuperont comme médecins ou comme infirmières mourront.

die. We do not acknowledge that and it is not taught. That proceeds right up to care. There is no preparation for the fact that you will meet dying people; how to look after them is not addressed. Student doctors in their final year have said to us, "I did not know that there would be so many dying people in hospitals." It upsets them. Our medical school provides more education in this area than others, and it is still grossly inadequate in our setting.

What we are proposing, therefore, is for mainstream educators and mainstream health care systems to embrace the need to prepare people in this area, as well funding it in hospitals and so on. Separate from that, I agree with what Mr. Ménard was saying about education. There is a large educational gap in what health care teams understand the law and good ethical practice to be. There is much confusion about that. I am not able to comment on whether we need more legislation because I am not a lawyer. In my opinion, more education, in terms of practice and law, would go a long way.

[Translation]

**Senator Pépin:** Thank you, Mr. Ménard, for your comment about how elderly people fear that they will not receive enough treatment and that age should not dictate the care that they receive. Some witnesses mentioned that even though they said and wrote down their last will, their directions were not respected. We were told that in some health care centres, patients gave their last will to the management of the centre and that it was not respected. Why were their directions not implemented? What can we do to ensure that they are? You hinted at an answer when you said that there was a lack of education and we have heard this a number of times since the beginning.

**Mr. Ménard:** When it comes to treating sick people, we still live in an old paternalistic culture. We do not view sick people as independent people. They are often reduced to their illness. It is like when a surgeon says: "This morning I am treating two spleens and three livers." You treat patients, not people. Legislation can only do so much in terms of changing these attitudes. Legislation reflects cultural values. In any law, the values and the choices of a culture are expressed. This is good, but we need to go further still. We need to educate ordinary people about these issues. We cannot just limit it to the medical environment, we need to empower people and inform them about their rights when it comes to their last wishes and how to implement them. We definitely have a long way to go before we bring an end to the vestiges of paternalism that permeate the entire health care system. Despite everything, the system is basically paternalistic. Legislation can only do so much to change this. I represent health care consumers. There are also victims of health care.

**Senator Pépin:** We also need to educate senior citizens.

On ne le leur dit pas. Ils passent directement dans le monde de la santé sans être préparés à la réalité du face à face avec des gens en train de mourir; on ne leur apprend pas comment s'en occuper. Les étudiants en dernière année de médecine nous disent: je ne savais pas qu'il y avait autant de gens qui mouraient dans les hôpitaux. Ça les bouleverse. Notre école de médecine offre plus de cours dans ce domaine que les autres et malgré tout, cela reste largement insuffisant.

Il faut en conséquence que les éducateurs préparent les étudiants dans ce domaine et que les hôpitaux, entre autres, prévoient les ressources nécessaires. Hormis cela, je suis d'accord avec les propos de M. Ménard sur l'éducation. Il y a un énorme vide dans l'éducation des équipes de santé en matière de droit et de déontologie. Il y a énormément de confusion. N'étant pas juriste, je ne peux pas vous dire si c'est une question de législation. À mon avis, enseigner ces questions de droit nous ferait déjà beaucoup progresser.

[Français]

**Le sénateur Pépin:** Je vous remercie, Me Ménard, de nous avoir dit que les personnes âgées craignent de ne pas avoir assez de traitement et que l'âge ne doit pas être l'indicateur des soins qu'ils recevront. Des témoins ont mentionné que même s'ils disaient et écrivaient leurs dernières volontés, leurs directives n'étaient pas appliquées. On nous a dit que dans certains centres de soins, les gens ont donné leurs dernières volontés à la direction de l'institution et qu'elles n'étaient pas respectées. Pourquoi ne sont-elles pas appliquées? Que pouvons-nous faire pour qu'elles le soient? Vous avez répondu un peu en disant qu'il y avait un manque d'éducation et cela nous a été répété dès le début.

**M. Ménard:** On vit encore dans une vieille culture de paternalisme à l'égard des personnes malades. On ne voit pas les personnes malades comme étant des personnes autonomes. On les réduit souvent à leur maladie. Un peu comme un chirurgien qui dit: ce matin, j'ai deux rates, trois foies à traiter. On traite les malades, on ne traite pas des personnes. La législation a une portée très limitée pour changer ces cultures. La législation exprime des valeurs culturelles. Dans toute loi, il y a des valeurs culturelles et des choix de société. Cela est utile mais il faut aller plus loin. Il faut accroître les connaissances de monsieur et madame tout-le-monde par rapport à ces choses. Il ne faut pas seulement informer le milieu médical, il faut faire ce que j'appelle de «l'empowerment» et informer les gens de leurs droits concernant leurs volontés de fin de vie et comment mettre celles-ci en oeuvre. Il y a certainement un chemin encore à franchir pour qu'on liquide, si l'on veut, les relents de paternalisme qui existent à travers tout le système de prestation de soins. Ce système demeure malgré tout foncièrement paternaliste. La législation a une portée limitée pour changer ces choses. Je représente des consommateurs de soins de santé. Il y a aussi des victimes des soins de santé.

**Le sénateur Pépin:** On doit aussi faire l'éducation des personnes du troisième âge.



**Mr. Ménard:** Yes, seniors have lived, for the most part of their lives, in a society where the doctor held the upper hand in the patient-doctor relationship. Long-term care patients find it very difficult to assert their will and their rights. People do not pay enough attention to what is happening.

**Senator Pépin:** When an emergency arises, they respond to the emergency, they were trained to provide care, they do not think to check if the patient has expressed the will not to be the object of extraordinary measures.

**Mr. Ménard:** This should be known in advance. The whole team should know the patient's wishes.

**Senator Pépin:** I am not lawyer but I have heard about section 12 of the Civil Code of Quebec. As you tried to explain it, there seems to be more openness or perhaps more lenience. If a Quebec patient is in another province and becomes seriously ill, would it be that province's law that would apply?

**Mr. Ménard:** Normally it is the law of the province of residence that applies. If a person in Quebec has expressed his verbal wishes to his loved ones, for example: if I am in a vegetative state, I do not want to be hooked up to a respirator, that is enough in Quebec. If that same person goes to Ontario and ends up in a vegetative state in Ontario, Ontario law requires a written directive to assert his wishes. Now, if the patient has no written directive in Ontario, what are they going to say: No, we will continue to use life support and continue to resuscitate every time there is a cardiac arrest, or should they follow the principle of the Quebec code where the family explains that there was a verbal communication whereby the patient made known his or her views to not be hooked up to a respirator for life support and should they respect those wishes? In the reconciliation that needs to be done, we are saying you need to be careful. Quebec law goes further. We would like these wishes to be respected when people are treated elsewhere.

[English]

**The Chairman:** Mr. Ménard, it is important to clarify just what the committee report said. The committee report did not recommend that we have a uniform advance directive across the country.

What we said is as follows — and I am quoting:

The committee recommends:

...the provinces and territories establish a protocol to recognize advance directives executed in other provinces and territories.

**Mr. Ménard:** We understand properly what the committee has reported. Our concern is a wish to avoid, in the process of implementing this principle, any sort of compromise.

**The Chairman:** That was never the intention, nor do I think it would ever be the intention.

**Mr. Ménard:** We are quite comfortable with that.

There is one more thing regarding the last page of our brief.

**M. Ménard:** Oui, ces gens du troisième âge ont vécu, pour une bonne partie, dans une société où le médecin décidait dans les relations patient-médecin. Les gens ont beaucoup de difficulté dans les soins de longue durée à faire valoir leurs volontés et leurs droits. La société ne regarde pas suffisamment ce qui se passe.

**Le sénateur Pépin:** Quand une urgence survient, ils répondent à l'urgence et comme ils ont été entraînés à donner des soins, ils ne pensent pas à vérifier si le patient a indiqué qu'il ne voulait pas recevoir des soins extraordinaires.

**M. Ménard:** Cela devrait être connu d'avance. Toute l'équipe devrait connaître les volontés du patient.

**Le sénateur Pépin:** Je ne suis pas avocate mais on parle de l'article 12 du Code civil du Québec. Comme vous avez essayé de nous l'expliquer, on semble être un petit peu ouvert ou peut-être un peu plus permissif. Si une patiente du Québec va dans une autre province et qu'elle tombe gravement malade, le code de cette province s'appliquera-t-il?

**M. Ménard:** C'est généralement la loi du domicile qui s'applique. Si la personne au Québec a exprimé des volontés verbales à ses proches, par exemple: si je me trouve dans un état neurovégétatif, je ne veux pas être liée à un appareil respiratoire, cela suffit au Québec. Si la personne s'en va en Ontario et qu'elle se retrouve dans un état neurovégétatif, la loi de l'Ontario prévoit une directive écrite pour faire valoir sa volonté. À ce moment, si la patiente n'a pas de directive écrite en Ontario, est-ce qu'on va dire: non, on va continuer à la maintenir et continuer à la réanimer tant qu'elle fera des arrêts cardiaques ou est-ce qu'on devrait suivre le principe du droit du Québec où la famille leur dit avoir été informée verbalement qu'elle ne voulait pas être maintenue en vie à l'aide d'un appareil respiratoire et respecter sa volonté? Dans la conciliation qu'il y aura à faire, nous vous disons de faire attention. La loi au Québec va un peu plus loin. Nous souhaiterions que ces volontés puissent être respectées lorsque les gens sont traités ailleurs.

[Traduction]

**La présidente:** Maître Ménard, il est important de préciser ce que disait notre rapport. Notre rapport ne recommandait pas une directive préalable uniforme pour tout le pays.

Nous disions simplement — et je cite:

Le comité recommande:

[...] Que les provinces et les territoires établissent un protocole pour reconnaître les directives préalables exécutées dans d'autres provinces et territoires.

**M. Ménard:** Nous comprenons très bien ce que votre comité a recommandé. Nous souhaitons simplement éviter, en appliquant ce principe, toute forme de compromis.

**La présidente:** Ce n'était pas du tout l'intention et je pense que cela ne le sera jamais.

**M. Ménard:** C'est parfait.

Il y a une chose de plus à propos de la dernière page de notre mémoire.



*[Translation]*

On the last page of our recommendations, the committee comments quickly on non-voluntary euthanasia. The Bar asks you not to open this question of mercy killing, according to the recommendations of your committee in 1995. There is no need for legislation on this issue.

*[English]*

**Senator Roche:** I congratulate the Catholic Health Association of Canada on an excellent brief. I even hope that some of your language, particularly in the concluding section, would find its way into our report.

Dr. Haughian, as you know, this committee is dealing with unanimous recommendations from 1995. Those recommendations, to be brief about it, centre around palliative care. Your brief, of course, has been extremely helpful, as have others, in insisting that the bases of palliative care must be increased.

A number of the witnesses who have come forward, despite the admonitions of the Chair, have drawn us into the areas on which there is not unanimity. In other words, they have raised the whole question of euthanasia and assisted suicide.

It seems that if people want to talk about euthanasia and assisted suicide, we say "Go over there," because, over here, in this committee, we are talking about, essentially, palliative care. I am concerned about whether it is totally realistic to separate the two.

In your brief, principle 5, number 17, you state that the withholding and withdrawal of treatment should be recognized as just one part of palliative care. You and I know what that means, but I am concerned that the public may not understand the distinctions that are made between withdrawal of care on the one hand, which is legitimate, legal and moral, and a form of euthanasia on the other. It is my impression that the public does not have this sophisticated understanding.

Maybe I am wrong, but that is what I think. Of course, in this respect, I am very pleased to note your call for increased education, first of all of the physicians and student physicians, and the public generally.

I am wondering what advice you might have for us when we do this report as to whether we can concentrate on palliative without going into the areas in which palliative care allows people to die in comfort and dignity. Can we completely separate the extended questions of euthanasia from our desire to let people die in comfort and peace?

**Dr. Haughian:** Senator Roche, I will pass this to Dr. Latimer. We have discussed this and I think she would like to respond to it.

**Dr. Latimer:** It is a good question. Perhaps we cannot entirely separate them. People that we see as patients and families understand what palliative care is when we very simply tell them what the term means in terms of comfort care. I had one patient

*[Français]*

À la dernière page de nos recommandations, le comité a glissé un mot à propos de l'euthanasie non volontaire. Le Barreau vous demande de ne pas ouvrir ce chapitre sur le meurtre par compassion selon les recommandations de votre comité en 1995. On n'a pas besoin de législation là-dessus.

*[Traduction]*

**Le sénateur Roche:** Je félicite l'Association catholique canadienne de la santé de son excellent mémoire. J'ose même espérer que certaines de vos propositions, surtout dans la conclusion, se retrouveront dans notre rapport.

Comme vous le savez, docteur Haughian, nos réunions portent sur les suites données à nos recommandations unanimes de 1995. Ces recommandations, pour aller au plus vite, concernaient en gros les soins palliatifs. Votre mémoire, bien entendu, est extrêmement utile, comme d'autres le sont, car il insiste sur la nécessité d'élever les bases des soins palliatifs.

Un certain nombre de nos témoins, malgré les admonestations de la présidence, nous ont entraînés dans des domaines où il n'y a pas unanimité. En d'autres termes, ils ont soulevé toute la question de l'euthanasie et de l'aide au suicide.

Il semble qu'à ceux qui veulent parler d'euthanasie et d'aide au suicide, nous disons: «Allez voir nos collègues», parce qu'ici, dans ce comité, nous ne parlons, pour l'essentiel, que de soins palliatifs. Je me demande s'il est vraiment réaliste de séparer les deux.

Dans votre mémoire, vous recommandez au numéro 17 que l'abstention et l'interruption du traitement soient reconnues comme étant seulement une partie des soins palliatifs. Vous et moi savons ce que cela signifie, mais je crains que le public ne comprenne peut-être pas la distinction qui est faite entre l'interruption de soins d'une part, qui est légitime, licite et morale et une forme d'euthanasie, d'autre part. J'ai l'impression que le public ne comprend pas cette distinction subtile.

Je me trompe peut-être, mais c'est ce que je pense. Bien entendu, à cet égard, je note avec très grand plaisir votre appel en vue d'une plus grande éducation, pour commencer de tous les médecins et de tous les étudiants en médecine, et du public en général.

Selon vous, quand nous rédigerons notre rapport, pourrions-nous nous concentrer sur les soins palliatifs sans parler des aspects des soins palliatifs qui permettent aux gens de mourir dans le confort et la dignité? Pouvons-nous isoler entièrement les questions reliées à l'euthanasie et notre désir de laisser les gens mourir dans le confort et la paix?

**Dr Haughian:** Sénateur Roche, je vais demander à Dre Latimer de vous répondre. Nous avons discuté de cette question et je pense qu'elle préférerait répondre.

**Dre Latimer:** C'est une bonne question. C'est peut-être impossible de séparer entièrement ces deux questions. Les patients et les familles comprennent ce que sont les soins palliatifs quand nous leur expliquons simplement que cela signifie des soins pour

many years ago who said, "I have never heard the word, but it sounds like a 'pal;' and do I ever need a pal."

I will never forget him because he taught me that that is what he needed — a pal with expertise. You can quickly tell people what palliative care is. They understand that it is not acting with the intention to take life.

However, it would not hurt to have continued dialogue about the differences.

The thing we must say about euthanasia is that it means acting with the intention to take life by a lethal injection. That is what it is. It would be very helpful in this country if, when we are using that word, that is what we are talking about. Assisted suicide, we know what that is, too.

Lay people seem intuitively to be able to grasp, particularly if they are supportively cared for, what the goals are — a state of calm, physical comfort, allowing nature to take its course, and assisting with symptom control.

My own view about focusing much on the euthanasia and assisted suicide issue is this — and we have also talked about this in the association: If we had everything in place for quality end-of-life care in Canada, then that would be one thing. Right now, I find it almost immoral for us to talk about taking people's lives when we have not done the harder task, which is to have palliative services in place for people.

We use the title, "The Luck of the Draw." It really is that way. In any city, in any centre, in any town, what you get depends on the luck of the draw. You could die very badly in Canada. There are people dying very badly in Canada.

I really feel that an interpretation of palliative care as to what it is and what we are aiming for can be readily accepted by the public. In fact, something is beginning to happen where towns are now, more than ever, beginning to want to have their own hospices. Lay people are beginning to raise funds for hospices in Canada, which resembles, to some degree, the United Kingdom system. I think people know what palliative end-of-life care is.

**Senator Roche:** Should we explicate in the committee's report what it is that we are not talking about here, in order to make the distinction clear?

**Dr. Latimer:** Yes, you could emphasize, in words as plain as they can be, just what palliative aims to do, including symptom control, sedation when it is necessary for symptom control, and then a very brief sentence about what it is not.

**Senator Roche:** A brief sentence? I do not know.

**Dr. Latimer:** Perhaps a brief paragraph.

assurer leur confort. Il y a bien des années, un de mes malades m'avait dit: «Je n'ai jamais entendu ce mot-là, mais il me donne l'impression d'un ami et j'ai vraiment besoin d'un ami.»

Je n'oublierai jamais ce malade parce qu'il m'a montré que c'est cela qu'il lui fallait: un ami possédant la compétence voulue pour l'aider. Il est facile d'expliquer aux gens ce que sont les soins palliatifs. Ils comprennent que le but n'est pas d'enlever la vie.

Ce serait cependant utile de poursuivre le dialogue sur les différences entre les deux choses.

Ce qu'il faut dire à propos de l'euthanasie, c'est qu'on agit avec l'intention d'enlever la vie en administrant une injection mortelle. C'est ce que c'est. Ce serait très utile de savoir que c'est de cela que nous parlons quand nous utilisons ce mot au Canada. Nous savons aussi ce qu'est l'aide au suicide.

Les profanes semblent pouvoir comprendre instinctivement, surtout s'ils reçoivent des soins de soutien, quels sont les objectifs des soins palliatifs, c'est-à-dire assurer le calme et le confort physique, permettre à la nature de suivre son cours et aider à contrôler les symptômes.

Voici ce que je pense de la possibilité de se concentrer sur l'euthanasie et l'aide au suicide, et nous en avons aussi discuté à l'Association: ce serait très bien de le faire si nous avions déjà tout ce qu'il faut pour assurer des soins de fin de vie de qualité au Canada. À l'heure actuelle, je trouve qu'il est presque immoral de parler d'enlever la vie à quelqu'un quand nous n'avons pas terminé la tâche plus difficile qui consiste à fournir de bons services palliatifs.

Nous avons utilisé le titre «Une question de chance» et c'est vraiment ce que c'est. Les services que vous obtiendrez dans une ville, un centre ou un village donné sont vraiment une question de chance. Vous pourriez mourir de façon tout à fait misérable au Canada. Il y a des gens qui meurent de façon misérable au Canada.

Je suis vraiment convaincue que le public est tout à fait prêt à accepter une description des soins palliatifs et des objectifs que nous visons. D'ailleurs, il y a maintenant de plus en plus de collectivités qui veulent avoir leurs propres hospices. Les profanes commencent à rassembler des fonds pour financer des hospices au Canada, ce qui nous rapproche dans une certaine mesure du système britannique. Je pense que les gens savent ce qu'on entend par soins palliatifs de fin de vie.

**Le sénateur Roche:** Devrions-nous préciser dans le rapport du comité de quoi au juste il n'est pas question dans le rapport pour que la distinction soit bien claire?

**Dre Latimer:** Oui, vous pourriez souligner de la façon la plus simple possible quels sont les objectifs des soins palliatifs, y compris le contrôle des symptômes et le recours aux sédatifs au besoin pour contrôler les symptômes, et expliquer ensuite dans une phrase très courte ce que cela ne comprend pas.

**Le sénateur Roche:** Une phrase très courte? Je ne vois pas comment.

**Dre Latimer:** Peut-être un bref paragraphe.



**The Chairman:** Senator Roche, I would like Dr. Latimer to comment on a statement you made. You talked about withdrawal of care and you put that together in a sentence with withdrawal of treatment. It seems to me that the two things are quite different. Continuation of care can co-exist with withdrawal of treatment.

Dr. Latimer, would you comment on that?

**Dr. Latimer:** Yes, I guess, suffice it to say, absolutely.

There was a physician in hospice care in the United Kingdom in 1982 who used to say that the question of whether or not to treat the patient is a false question. Granted, in those days a lot of the issues were framed around to treat or not to treat. The real question, he said, is this: How shall we treat the patient? His other question related to care: How shall we care for the patient? Asking those questions allowed him to talk about active palliative treatment, which is a combination of medical health care expertise and the psychosocial support of a whole person.

That reminds me to say that there is still one area that needs a fair bit of education amongst health care planners, and that is the false belief that palliative care is a passive, hand-holding, do-nothing kind of approach. Consequently, health care planners tend to think that it should be inexpensive and that volunteers can probably do it all. Volunteers are very helpful, but there is a great need for medical health care expertise in ministries, with hospital CEOs, health councils, and so on.

**Dr. Haughian:** In answer to your question, Senator Roche, the way we develop our briefs is a model we would suggest, even in terms of educating the public. The emphasis is on care of the dying person, but we clearly state the context. For example, on page 4, we clearly state that we are not talking about euthanasia and assisted suicide. That must be constantly repeated in whatever education we do and in your report.

**Senator Roche:** One of the unanimous recommendations of the committee was that government should establish a third category of murder, which would not carry a mandatory life sentence, and so on.

What is the position of the Catholic Health Association of Canada on that recommendation, which has been revisited by witnesses who have come before the committee? They have tossed it back here on the table again. Some think it is wise; some think it is unwise. Does the Catholic Health Association of Canada have a position on the establishment of a third category of murder for what is called compassionate homicide?

**Dr. Haughian:** Yes, the Catholic Health Association of Canada does have a position. If we go back to the brief that we presented earlier, we state quite clearly that we do not agree with that. It does not take seriously what "euthanasia" and "assisted suicide" really mean. It will demean the person who is the object of that type of act.

**La présidente:** Sénateur Roche, je voudrais que Dre Latimer commente ce que vous venez de dire. Vous avez parlé de retirer les soins dans la même phrase que le retrait du traitement. Il me semble que ce sont deux choses bien différentes. On peut continuer les soins même si l'on retire le traitement.

Qu'en pensez-vous, docteure Latimer?

**Dre Latimer:** Oui, tout à fait.

Un médecin spécialisé dans les soins à l'hospice au Royaume-Uni en 1982 avait l'habitude de dire que la question n'est pas de savoir si l'on doit traiter le malade ou non. Bien sûr, à l'époque, une bonne partie du débat portait sur la décision de traiter ou de ne pas traiter. D'après ce médecin, la question qu'il fallait poser était: «Comment allons-nous traiter le malade?» Son autre question avait trait aux soins: «Comment allons-nous soigner le malade?» Le fait de poser ces questions permettait à ce médecin de parler de traitement palliatif actif, qui combine les services de soins médicaux et les services de soutien psychosociaux.

Cela me rappelle qu'il y a encore un mythe auquel on devrait sensibiliser les planificateurs des soins de santé, soit le mythe voulant que les soins palliatifs sont quelque chose de passif, où l'on se contente de tenir la main du malade sans faire quoi que ce soit. Les planificateurs des soins de santé ont tendance à croire que ces soins sont peu dispendieux et que les bénévoles peuvent probablement tout faire. Les bénévoles font beaucoup, mais il faudrait aussi des gens bien renseignés sur les soins de santé médicaux dans les divers ministères, parmi les PDG d'hôpitaux, aux conseils de santé, et ainsi de suite.

**Dr Haughian:** Pour répondre à votre question, sénateur Roche, vous pourriez trouver dans nos mémoires une façon d'expliquer la situation, même pour le public. Nous insistons sur les soins pour la personne au terme de sa vie, mais nous expliquons clairement dans quel contexte. Par exemple, à la page 3, nous disons clairement qu'il ne s'agit pas d'euthanasie ou d'aide au suicide. C'est une chose que nous devons répéter constamment dans nos programmes d'éducation et que vous devriez répéter dans votre rapport.

**Le sénateur Roche:** L'une des recommandations formulées à l'unanimité par tous les membres du comité, c'est que le gouvernement devrait créer une troisième catégorie de meurtre, qui ne serait pas passible d'une peine d'emprisonnement à perpétuité, par exemple.

Quelle est la position de l'Association catholique canadienne de la santé à ce sujet vu que les témoins précédents ont déjà donné leur avis? Les autres témoins sont revenus là-dessus. Certains trouvent que c'est une bonne chose et d'autres non. L'Association catholique canadienne de la santé a-t-elle une opinion sur la création d'une troisième catégorie de meurtre pour ce qu'on appelle l'homicide par compassion?

**Dr Haughian:** Oui, l'Association catholique canadienne de la santé a une position à ce sujet. Dans le mémoire que nous avons présenté plus tôt, nous disons très clairement que nous ne sommes pas d'accord là-dessus. Une telle mesure ne reflète pas vraiment la signification de l'euthanasie et de l'aide au suicide. Cela dévaloriserait la personne qui fait l'objet d'un tel acte.



We are concerned about the disabled, the vulnerable, the handicapped, et cetera. Generally, we do have a position on it. We are against that type of compassionate suicide. We do not address it in this brief because it was our understanding that the issue was not under study by this committee. We outlined our position in our previous brief, and we confirm that again.

**Senator Roche:** I wish to make a slight correction. Because it was a unanimous recommendation, then we would be dealing with it, would we not?

**The Chairman:** We may or may not, depending on what the committee decides. Senator Corbin made it clear yesterday that, while it was unanimous on the day it was tabled, it was not unanimous three weeks later.

**Senator Roche:** Right. In any event, do I understand, Dr. Haughian, that in your first testimony, in 1994, you did deal with this question?

**Dr. Haughian:** We did deal with it and our position has stayed the same.

**Senator Roche:** I will go back and read it.

**Senator Corbin:** On that very point, it was unanimous in the report as tabled on June 6, 1995. As I said yesterday, I was unavoidably absent, having been sent on a mission outside the country. Therefore, I was not in a position to express my opposition to that clause. However, at debate stage in the Senate, following the tabling of the report, I did so. It may be unanimous in the text, but it certainly was not unanimous in spirit. That is another issue.

May I ask whether or not these written presentations this morning will be appended to the proceedings of the committee? I think they are excellent presentations, compared to others. I hate comparisons, but they are extremely well presented and they state the issues quite clearly.

**The Chairman:** As you know, Senator Corbin, it is not the custom to append any brief unless the committee recommends otherwise.

**Senator Corbin:** Yes, unless the committee indicates otherwise.

**The Chairman:** However, we would not be operating equally with all other presentations if we made exceptions. I concur that these were excellent presentations today. They will form a body of the documentation that will be held in the Library of Parliament.

**Senator Corbin:** But will the public who will be viewing our proceedings later on or reading our proceedings be able to request copies of these presentations, and will they be sent out?

**The Chairman:** Absolutely.

**Senator Corbin:** I have four questions, not comments.

First, I think it was Dr. Latimer who referred to the research issue, was it?

Nous nous inquiétons des personnes handicapées ou vulnérables. Nous avons donc une position à ce sujet. Nous nous opposons à l'homicide par compassion. Nous n'en parlons pas dans notre mémoire parce que nous avons l'impression que votre comité ne voulait pas se pencher sur cette question. Nous avons expliqué notre position dans notre mémoire précédent et nous sommes toujours du même avis.

**Le sénateur Roche:** Je voudrais faire une mise au point. Vu que c'était une recommandation unanime, nous devons nous en occuper, n'est-ce pas?

**La présidente:** Cela dépendra de ce que décidera le comité. Le sénateur Corbin a bien dit hier que le rapport était unanime le jour de son dépôt, mais qu'il ne l'était plus trois semaines plus tard.

**Le sénateur Roche:** Très bien. De toute façon, vous avez bien dit, docteur Haughian, que vous aviez parlé de cette question lors de votre premier témoignage en 1994?

**Dr Haughian:** Nous en avons parlé et notre position n'a pas changé.

**Le sénateur Roche:** J'irai lire votre témoignage.

**Le sénateur Corbin:** À ce sujet, cette recommandation avait été appuyée à l'unanimité dans le rapport déposé le 6 juin 1995. Comme je l'ai dit hier, je ne pouvais pas être là comme j'avais été envoyé en mission à l'extérieur du pays. Je n'avais donc pas pu exprimer mon opposition à cet article. Je l'ai cependant fait lors du débat au Sénat après le dépôt du rapport. On dit peut-être qu'il s'agissait d'une recommandation faite à l'unanimité dans le rapport, mais il n'y avait pas unanimité en réalité. C'est une autre question.

Puis-je demander si le texte des mémoires de ce matin sera annexé au compte rendu des délibérations du comité? Je pense que ces mémoires sont excellents, comparativement à d'autres. Je déteste les comparaisons, mais ils sont extrêmement bien présentés et les questions y sont énoncées très clairement.

**La présidente:** Vous savez, sénateur Corbin, qu'un mémoire n'est pas habituellement annexé, à moins que le comité en décide autrement.

**Le sénateur Corbin:** Oui, à moins que le comité en décide autrement.

**La présidente:** Cependant, si nous faisons des exceptions, nous ne traiterions pas également tous les autres témoins qui apportent des mémoires. Je conviens avec vous que nous avons reçu aujourd'hui d'excellents mémoires. Ils feront partie de la documentation conservée à la Bibliothèque du Parlement.

**Le sénateur Corbin:** Mais les gens qui verront plus tard l'enregistrement magnétoscopique de nos délibérations ou qui en liront le compte rendu pourront-ils demander des copies de ces mémoires, et les recevront-ils?

**La présidente:** Mais bien sûr.

**Le sénateur Corbin:** J'ai quatre questions à poser: ce ne sont pas des commentaires.

Premièrement, je pense que c'est Dre Latimer qui a fait allusion à la question de la recherche, n'est-ce pas?

**Dr. Latimer:** Yes.

**Senator Corbin:** On page 11, you recommend that "research funding bodies (both government and private) be encouraged to support research in palliative care." Is there much private funding available at this stage with respect to that sort of initiative? How could we encourage private enterprise or individuals to donate more? I agree with you that area deserves extreme attention.

**Dr. Latimer:** There is not a lot of private funding available. As to encouraging more donations, I think the interpretation of palliative care into a mainstream agenda, both for society and for health care, would help.

As well, we had said in the brief that we would like to see palliative and end-of-life care on the main agenda in health care planning and, for society as well, these sorts of issues and familiarity. That translation to industry or other private groups would then occur, either individually or on a national basis.

**Senator Corbin:** But there does not seem to be a concerted interest in funding this sort of research.

**Dr. Latimer:** Not at the moment, no.

**Senator Corbin:** The drug companies could be doing more. They are all well off.

**Dr. Latimer:** Yes.

**Senator Corbin:** I am passing the message on publicly. First, of all people, they should be doing more.

**Dr. Latimer:** In some fairness to them, they do support a fair bit of education in palliative care in Canada, but they might have an interest in the research area. There is a group in the United States, the Robert Wood Foundation, which has a lot of holdings, and they are behind a huge physician education project in end-of-life care. That project is just beginning. That is one example of where a foundation might be drawn into funding.

**Senator Corbin:** Well, the message is out there, for what it is worth.

[Translation]

Sister Noël, I had a quick look at the code of ethics that you provided for us. There is so much in there that I have to ask myself how health care practitioners manage to make any sense of it all. I think that ethics standards are probably taught at university. Associations and institutions each have their own code of ethics. The religious factor figures into it, some take it into consideration and others do not. There must be some basic element when it comes to drafting codes of ethics. What has your experience been with respect to this? I am sure that you have had to deal with patients who have different opinions when it comes to

**Dre Latimer:** En effet.

**Le sénateur Corbin:** À la page 11, vous recommandez «que l'on encourage les organismes de financement publics et privés à soutenir la recherche en matière de soins palliatifs.» Est-ce qu'il y a un financement privé important qui est disponible actuellement pour une initiative de cette nature? Comment pourrions-nous encourager des entreprises privées ou des particuliers à donner davantage? Je suis d'accord avec vous pour dire que cette question mérite énormément d'attention.

**Dre Latimer:** Il n'y a pas beaucoup d'aide financière de la part du secteur privé. Pour ce qui est d'encourager les gens à donner davantage, je pense qu'il serait utile d'inclure les soins palliatifs dans un programme général, tant pour la société que pour les soins de santé.

En outre, nous avons dit dans notre mémoire que nous aimerions voir inclure les soins palliatifs et les soins de fin de vie dans le programme principal de planification des soins de santé et à l'intention de la société également, pour familiariser les gens avec les questions de cette nature. Ces notions seraient ensuite adoptées par l'industrie ou d'autres groupes privés, individuellement ou sur une base nationale.

**Le sénateur Corbin:** Mais il ne semble pas y avoir d'intérêt concerté pour le financement de la recherche dans ce domaine.

**Dre Latimer:** Non, pas pour l'instant.

**Le sénateur Corbin:** Les entreprises pharmaceutiques pourraient faire davantage. Elles sont toutes riches.

**Dre Latimer:** En effet.

**Le sénateur Corbin:** Je transmets le message publiquement. Ce sont elles avant tout qui devraient faire davantage.

**Dre Latimer:** Je signale en toute justice pour elles qu'elles aident beaucoup à la formation dans le domaine des soins palliatifs au Canada, mais elles pourraient manifester un intérêt pour la recherche. Il existe un groupe aux États-Unis, la Robert Wood Foundation, qui possède des actifs nombreux, et qui subventionne un énorme projet de formation des médecins en soins de fin de vie. Ce projet n'en est qu'à ses débuts. Il s'agit d'un exemple du type de financement qui pourrait attirer une fondation.

**Le sénateur Corbin:** Eh bien, voilà, le message est transmis.

[Français]

Sœur Noël, j'ai regardé rapidement le code d'éthique que vous avez mis à notre disposition. Il y en a tellement que je me demande comment les praticiens de la santé arrivent à voir la lumière dans tout cela. On enseigne probablement des normes d'éthique à l'université. Différentes associations et institutions ont leur propre code d'éthique. Le facteur religieux entre en ligne de compte, certains en veulent et d'autres n'en veulent pas. Il doit y avoir une donnée fondamentale concernant la rédaction des codes d'éthique. Quelle a été votre expérience dans ce domaine? Je suis certain que dans vos activités, vous avez affaire à des patients ou



life and death. How do you manage to reconcile all of these different perspectives? It cannot be done with one code of ethics.

**Ms Noël:** What colours my thoughts is my experience in health care in Catholic institutions. Fundamentally, ethics relate to life. People have a lot in common when it comes to the respect and dignity of life. It is rare that other religions run contrary to this respect.

[English]

**Dr. Haughian:** Senator Corbin, that is a very good question. In the process of producing this ethics guide, there was wide consultation not only among Catholics or Christians, but also feedback from medical associations and nursing associations was solicited. This guide is used widely in Catholic and Christian-based institutions, but we also find it is used outside of that context.

From a careful read of many of the articles that we have here, and the values on which they are based, you will discover that are not specifically Catholic. They have grown up within a Christian context, but they very much express many of the values and principles that are more and more accepted within the general medical and nursing community.

If we were to compare this to other codes of ethics, you would find more agreement than disagreement. Though different groups are developing different codes, there are many of areas of agreement. For example, our association sits down with the CMA, the CNA, and the CHA to draw together joint statements related to ethics and we have much agreement in terms of those principles. I believe that there is a place for individual codes, and you will find that there is much agreement on the basic principles underlying those.

[Translation]

**Senator Corbin:** A number of previous witnesses underlined this problem of the mandate over time. A mandate is drafted in 1990 or in 1994 and end-of-life decisions are being made in the year 2005. Does this mandate still apply? Medical and legal concepts evolve. What value or what importance should be ascribed to a mandate that is getting old and that has not been renewed with time?

**Ms Deleury:** That is an important question. The mandate contains the guidelines that have been conferred to a mandatary who will apply them because they represent the patient. Obviously, a mandate of this type will be entrusted to someone that you know very well and who in turn knows you very well and who will, in theory, be able to adapt his or her response or attitude according to your personality. Indeed, things do evolve very quickly.

You brought up the issue of information and of the exchange that needs to take place when drafting the mandate. The current trend is to use prepared forms. People do not take the time to discuss it, to think about it. When we talk about education, it

patientes qui ont des vues différentes sur la valeur de la vie et de la mort. Comment arrivez-vous à concilier tous ces points de vue? On ne peut pas le faire avec un seul code d'éthique.

**Mme Noël:** Ce qui influence ma réflexion est mon expérience dans les soins de santé dans des établissements catholiques. À la base, toute éthique touche à la vie. On se rejoint énormément dans ce qu'il y a de respect et de dignité de la vie. J'ai rarement rencontré des choses contraires à cela dans d'autres religions.

[Traduction]

**Dr Haughian:** Sénateur Corbin, c'est une excellente question. Pendant la préparation de ce code d'éthique, on a consulté non seulement des groupes catholiques ou chrétiens, mais on a aussi demandé la réaction de représentants d'associations médicales et des associations d'infirmiers et d'infirmières. Ce guide est largement utilisé dans les établissements catholiques et chrétiens, mais nous constatons qu'on l'utilise également ailleurs.

Si vous lisez attentivement plusieurs des articles que nous présentons ici, et si vous examinez les valeurs sur lesquelles ils sont fondés, vous constaterez qu'il ne s'agit pas de notions spécifiquement catholiques. On a élaboré ce guide dans un contexte chrétien, mais il reflète beaucoup de valeurs et de principes acceptés de plus en plus dans l'ensemble des milieux médicaux et infirmiers.

Si nous comparions ce guide à d'autres codes déontologiques, vous verriez plus de points communs que de divergences. Bien que d'autres groupes élaborent des codes différents, ils comportent de nombreux points communs. Par exemple, notre association discute avec les représentants de l'Association médicale canadienne, de l'Association des infirmières et infirmiers du Canada et de l'Association canadienne des soins de santé pour préparer ensemble des déclarations au sujet des questions de déontologie et nous nous entendons très bien pour ce qui est des principes. Je crois qu'il peut exister différents codes, mais vous constaterez qu'il y a convergence d'opinions quant aux principes fondamentaux qui les sous-tendent.

[Français]

**Le sénateur Corbin:** La problématique du mandat échelonné dans le temps a été soulignée par des témoins précédents. On rédige un mandat en 1990 ou en 1994 et on se trouve en situation de fin de vie en l'an 2005. Ce mandat a-t-il encore de la valeur? La médecine et les concepts légaux évoluent. Quelle antériorité ou quelle importance doit-on attacher à un mandat qui prend de l'âge et qui n'est pas renouvelé dans le temps?

**Mme Deleury:** La question est importante. Le mandat contient des lignes directrices qui ont été confiées à un mandataire qui les appliquera parce qu'elle représente la personne. Évidemment, un mandat de cette nature sera confié à quelqu'un que vous connaissez très bien et qui vous connaît aussi très bien et qui doit, en principe, être capable de pouvoir adapter sa réponse ou son attitude en regard de votre personnalité. Effectivement, les choses évoluent très vite.

Vous soulevez le problème de l'information et de l'échange qui doit avoir lieu au moment de la rédaction du mandat. La tendance actuelle est d'avoir des formules toutes faites. On ne prend pas le temps d'en discuter, d'y réfléchir. Lorsqu'on parlait d'éducation, il



seems to me that we must provide more information and we must promote more discussion between the mandator and the mandatar. People need to learn more about the nature of treatments in different circumstances in order to ensure that the decisions made by the mandatar reflect the true wishes of the mandator. Here, the issue of information and education becomes essential.

There may be a trend to use pressure — in the current context where there are large numbers of seniors who are entering these long-term care centres — to ask the people entering these institutions to sign a mandate a bit too quickly.

However, there are long-term care centres that are holding information sessions, which allow for the exchange of information which will lead to the signing of a mandate. Once again, it is an issue of culture and information.

**Mr. Ménard:** In any case, section 12 allows a person to express different wishes later. It is flexible and even if it is not written, there is no problem. The idea is to know the wishes of the person and not the form used to express these wishes. Even if a mandate was given in 1995, and the treatment is being given in the year 2005, if the person said in 2005 that they wanted something different, then the mandate is ignored. It is the most recent wishes that override and as soon as the person indicates they have changed their mind, then that is what is respected.

**Ms Vadboncoeur:** We need to emphasize — and this comes back to the need for education — the confidence that must exist between the mandator and the mandatar. This link is extremely important. The mandatar must be able to know, or even guess if need be, not only the needs, but also the comfort wishes of the person that they represent. We need to educate people to urge them to entrust this mandate to someone in whom they have complete confidence in order to avoid, 15 years later, any disagreements.

[English]

**Senator Corbin:** I wish to address this question to the other group, perhaps Dr. Latimer or whoever wishes to respond.

On page 9 of your brief, under "Care for Patients and Families," you raise a familiar theme. You talk about the effects of restructuring and downsizing health services across Canada affecting palliative care. That is a passing phenomenon, if I may suggest. I hope it does improve. I do not downgrade the serious concern you have in this respect.

More fundamentally, do governments across Canada have serious palliative care policies or not?

**Dr. Latimer:** We have a recommendation about that in the brief, that they must be developed. No, to my knowledge there is not a province that has a serious palliative care policy. Some provinces, like Ontario and others, are funding some education initiatives that are very helpful for practising health care professionals. They are not large initiatives, but they do exist. When it comes to policy for patient services, where one could say, "In X province every person in this situation will be able to

m'apparaît qu'une promotion doit être faite dans le sens d'une plus grande information et de la nécessité qu'il y ait une discussion entre le mandant et le mandataire. Il faut qu'on s'informe davantage de la nature de ces soins dans telle ou telle circonstance afin que les agissements du mandataire reflètent les volontés réelles de la personne qui l'a mandaté. Ici la question de l'information et de l'éducation devient primordiale.

Il y a peut-être une tendance à exercer des pressions — dans le contexte actuel où on parlait de la multiplicité des personnes âgées qui entrent dans des centres d'hébergement de longue durée — pour demander aux personnes qui entrent dans ces établissements de signer un mandat un peu rapidement.

Par contre, il y a aussi des centres d'hébergement de longue durée qui font des séances d'information, qui permettent des échanges qui vont donner lieu à la signature d'un mandat. Ici encore, c'est une question de culture et d'information.

**M. Ménard:** De toute façon, l'article 12 permet toujours à la personne d'exprimer d'autres volontés ultérieures. C'est flexible et même si ce n'est pas par écrit, ce n'est pas grave. On veut connaître les volontés de la personne et non pas la forme utilisée pour l'exprimer. Même si un mandat a été donné en 1995 et que les soins ont lieu en 2005, si la personne nous dit en 2005 qu'elle veut autre chose, on oublie le mandat. C'est une volonté exprimée à un moment et dès que la personne manifeste qu'elle a changé d'idée, on va en ce sens.

**Mme Vadboncoeur:** Il faut mettre l'accent — et on rejoint ici le besoin d'éducation — sur le lien de confiance qui doit exister entre le mandant et le mandataire. Ce lien doit être énorme. Le mandataire devrait pouvoir connaître, deviner même au besoin, non seulement les besoins mais aussi les désirs et les souhaits de confort de la personne qu'il représente. Il y a une nécessité d'éduquer les gens afin de les inciter à confier ce mandat à quelqu'un en qui ils ont une entière confiance de façon à éviter que, 15 ans plus tard, la personne ne soit plus du tout d'accord.

[Traduction]

**Le sénateur Corbin:** Je pose ma question aux membres de l'autre groupe, peut-être à la Dre Latimer ou à un autre témoin qui voudrait répondre.

À la page 9 de votre mémoire, sous le titre «Soins dispensés aux patients et à leur famille», vous soulevez un thème familial. Vous dites que la restructuration et la réduction des services de santé se répercutent sur les soins palliatifs dans l'ensemble du Canada. C'est un phénomène passager, à mon avis. Je ne veux pas minimiser la gravité de vos préoccupations à cet égard.

Je trouve plus essentiel de savoir si les différents gouvernements du pays ont ou non une politique valable en matière des soins palliatifs.

**Dre Latimer:** Nous formulons dans notre mémoire une recommandation à cet effet. Mais à ma connaissance, il n'y a pas une province qui a une politique valable en matière de soins palliatifs. Certaines provinces, comme l'Ontario et d'autres, financent des initiatives de formation qui sont très utiles pour les professionnels de la santé. Il ne s'agit pas d'initiatives importantes, mais elles existent. En ce qui concerne la politique relative aux services aux patients, on ne peut pas dire que dans

receive, if it be their choice, the following range of services and we will fund those services," that has not happened.

I should mention a word about funding because it is important and we were talking last evening about the cost of a palliative care consultation team in a hospital.

It is my belief that, yes, it costs money, but the cost is so infinitesimal compared to the global budgets of hospitals at the present time that we cannot easily accept that money could not be found. Recognizing that there are problems with money, it is a question of shifting some priorities.

If we were to see a consultation/collaborative care team in every hospital in Canada as a beginning step, with some outreach function into the community, that would go a long way to getting things under way, also coupled with education of all professionals and practising physicians.

**Senator Corbin:** Dr. Ayoub appeared before this committee yesterday but left before we could question him. He insisted, as have other witnesses in the past and during the current exercise, on the continuum of care. How many governments have bought into that concept of continuum of care? This is what palliative care is all about, whether you live in big cities, in private or in public institutions, regardless. I have the impression that we do not have that continuum of care.

**Dr. Latimer:** No, we do not.

**Senator Corbin:** Governments have not focused on it.

**Dr. Latimer:** Also, communities have not been charged with examining that continuum. We have in the appendix of our brief, a document — I was involved with the OMA — that talks about programs for palliative care. It suggests a continuum, a seamless system of care, in which a patient can fairly readily move amongst all the settings that he or she may require. Like Mrs. J.H. in our submission today, a patient should be able to move from hospital to home and to an in-patient palliative setting.

We could count on the fingers of one hand how many of those systems exist in Canada. With funding and coordinated planning, communities could perhaps develop the systems at their own level, but there needs to be a mandate from above that this must be developed.

Similar to education, the medical schools, I feel confident, could fairly quickly move to education if, in some very nice way, they were told that they had to do it.

**The Chairman:** We will do our best, Dr. Latimer.

**Dr. Latimer:** You have to be nice and firm.

une province donnée, toute personne qui se trouve dans cette situation pourra bénéficier, si elle le désire, de toute une gamme de services et que la province en assumera le coût.

Je dois dire un mot au sujet du financement, parce que c'est important. Hier soir, nous parlions du coût d'une équipe de consultation en soins palliatifs dans un hôpital.

Je crois en effet qu'il y a un coût, mais ce coût est tellement infime comparativement aux budgets globaux des hôpitaux à l'heure actuelle que nous ne pouvons pas facilement accepter qu'on nous réponde qu'il est impossible de trouver l'argent. Nous reconnaissons qu'il y a des problèmes sur le plan financier, mais il s'agit de changer certaines priorités.

Si l'on instituait une équipe de consultation et de collaboration en matière de soins dans chaque hôpital du Canada, comme point de départ, en y intégrant des activités de contact avec la collectivité, ce serait un très bon début, surtout si l'on y joignait un programme de formation à l'intention des médecins et de tous les professionnels de la santé.

**Le sénateur Corbin:** Le docteur Ayoub a comparu hier devant le comité, mais il a dû partir avant que nous puissions lui poser des questions. Il a insisté, comme d'autres témoins l'avaient déjà fait dans le passé et encore dernièrement, sur le continuum des soins. Combien de gouvernements ont adopté ce concept de continuum des soins? C'est cela les soins palliatifs, peu importe qu'on vive dans une grande ville, qu'on soit dans un établissement privé ou public. J'ai l'impression que le continuum des soins n'existe pas.

**Dre Latimer:** Non, il n'existe pas.

**Le sénateur Corbin:** Les gouvernements n'y ont pas accordé d'importance.

**Dre Latimer:** En outre, on n'a pas demandé aux collectivités d'examiner cette question du continuum. Nous avons joint en appendice à notre mémoire un document — j'ai participé aux consultations de l'Ontario Medical Association — où il est question de programmes de soins palliatifs. On y parle d'un continuum, d'un système sans failles de soins, où chaque patient pourra assez facilement passer d'un établissement ou d'un département à un autre selon ses besoins. Comme dans l'exemple de Mme J.H. que nous avons donné dans notre mémoire aujourd'hui, un patient devrait pouvoir passer de l'hôpital à son domicile ou être hospitalisé dans un établissement de soins palliatifs.

Nous pourrions compter sur les doigts de la main le nombre d'endroits où c'est possible au Canada. Avec le financement nécessaire et une planification coordonnée, les collectivités pourraient peut-être élaborer de tels systèmes à leur propre niveau, mais il faut qu'un mandat leur vienne d'en haut.

Je suis également convaincue que les écoles de médecine pourraient aussi offrir assez rapidement la formation nécessaire, si on leur disait, en termes très diplomatiques, qu'elles doivent le faire.

**La présidente:** Nous ferons de notre mieux, docteure Latimer.

**Dre Latimer:** Il faut être poli mais ferme.



**Senator Corbin:** I am not a partisan person, so do not attach that notion to what I am about to say, but Premier Harris of Ontario, more and more often, is making pronouncements and dictating how certain things should be done in schools with respect to teachers, programs, pupils. It happened again yesterday or the day before.

I never hear any comments from above from anybody, regardless of political colour, concerning palliative care, that one ought to do this and one ought not to do that. What is wrong? We are dealing with young people and, in many cases, middle-aged people but mostly with senior citizens who have given their lives to building this country, yet we seem to neglect them, to forget them. That is the crying shame of the lack of governmental policies in this era.

**Dr. Latimer:** One thing you might want to consider is using the phrase "palliative end-of-life care." Some people in acute care hospitals and other settings — and maybe the premier himself — may think that palliative care is something that is done "over there," done by nice people, but over there and so therefore not important. Moving it to centre stage might be assisted by combining an "end of life" phrase with palliative care.

**Senator Keon:** Ms Deleury, you described an extensive experience with advance directives in your province. I have had limited experience with them in my professional life as a heart surgeon. When I have seen conflicts between designated responsible people and the health care team, it has usually occurred when the palliative care experts had not been involved early enough, or in a rather acute situation where there had not been time to involve the palliative care experts.

In your extensive experience, have you been able to see the incidents of conflict between the designated responsible person and the health care team and whether there was a correlation between those incidents and the involvement of professional palliative care?

[Translation]

**Ms Deleury:** The conflicts which you refer to can, and indeed do, occur. However we have to acknowledge that patients today are much more assertive with respect to their rights. My colleague Jean-Pierre Ménard mentioned that there was a certain resistance, given the hospital culture particularly, that we need to consider. Nonetheless, in the case of a conflict between the medical professionals and the mandatary, the mandatary can assert that if the wishes of the patient are not respected, legal action may be taken. It remains a clash between the very powerful and the very weak. Sometimes, some of them are less demanding than they would like to be, given the somewhat imposing structure that they have to deal with, thus the gap that we were talking about earlier between the legal statutes, the standards and the practices.

**Le sénateur Corbin:** Je ne veux pas que vous voyiez un parti pris dans ce que je vais dire, mais le premier ministre Harris de l'Ontario fait de plus en plus souvent des déclarations dans lesquelles il dicte la façon dont certaines choses doivent se faire dans les écoles, en ce qui concerne les enseignants, les programmes d'étude, les élèves. C'est arrivé encore hier ou avant-hier.

Je n'entends jamais de commentaires venant d'en haut, de quiconque, peu importe le parti politique, au sujet des soins palliatifs, sur ce qu'il faudrait faire ou ne pas faire. Qu'est-ce qui ne va pas? Il s'agit de jeunes personnes, dans bien des cas, de personnes d'âge moyen, mais surtout, de personnes âgées qui ont donné leur vie pour bâtir ce pays. Nous semblons pourtant les négliger, les oublier. Voilà ce qu'il y a de vraiment honteux dans le manque de politiques gouvernementales à notre époque.

**Dre Latimer:** Vous pourriez songer à employer l'expression «soins palliatifs de fin de vie». Certaines personnes dans les hôpitaux de soins de courte durée et ailleurs — peut-être même le premier ministre — pourront croire que les soins palliatifs sont quelque chose que font «ailleurs» de gentilles personnes, mais ailleurs, et par conséquent, de peu d'importance. Pour lui redonner son importance, on pourrait ajouter à l'expression «soins palliatifs» les mots «de fin de vie».

**Le sénateur Keon:** Madame Deleury, vous avez dépeint une expérience importante des directives préalables dans votre province. J'ai moi-même peu d'expérience en la matière, dans ma vie professionnelle de cardiochirurgien. Quand j'ai vu des conflits entre les personnes désignées responsables et l'équipe des soins de santé, il s'agissait habituellement de situations où on n'avait pu faire intervenir les experts en soins palliatifs suffisamment tôt, ou dans des situations d'urgence, où il n'y avait pas eu suffisamment de temps pour cette intervention.

D'après votre longue expérience, avez-vous vu des incidents de conflit entre les personnes désignées responsables et l'équipe de soins de santé? Y a-t-il alors un lien entre ces incidents et la participation des professionnels des soins palliatifs?

[Français]

**Mme Deleury:** Les conflits auxquels vous faites référence peuvent se présenter et se présentent effectivement. Il faut quand même convenir du fait que les patients se montrent aujourd'hui beaucoup plus agressifs en regard du respect de leurs droits. Mon collègue Jean-Pierre Ménard mentionnait qu'une certaine résistance, compte tenu de la culture hospitalière plus particulièrement, est à prendre en compte. Il n'en demeure pas moins qu'en cas de conflit entre la vision du corps médical et celle du mandataire telle que véhiculée par son mandat, le mandataire peut faire valoir que dans l'hypothèse où il ne respecterait pas cette volonté, il y aurait possibilité d'une poursuite. Il demeure que c'est toujours l'affrontement entre le plus fort et le plus faible. Parfois, certains vont peut-être moins revendicateurs qu'ils ne voudraient l'être, compte tenu du caractère un peu imposant de la structure à laquelle ils doivent faire face, d'où l'écart dont on parlait tout à l'heure entre les textes de loi, les normes et les pratiques.



One must however acknowledge that there have been some changes in the past 10 years. My colleague Mr. Ménard could speak at length on those changes that occurred in hospital culture.

**Mr. Ménard:** It is important to know that the decision-making authority of the designated representative, the mandatary is specifically defined in Quebec law. In other words, the mandatary cannot make any decision he wants. He has to act in the interests of the person he represents, taking into account that person's will and making sure that the care is beneficial and appropriate, and that the risks are not out of proportion with the benefits. The law provides that if the health care team does not act in the interest of the person, according to the mandatary, the representative can bring the case before the courts. In Quebec, it is done quite regularly under the new legislation. The new section 16 of the Civil Code provides that the mandatary may get the merits of the decision tested. The courts make a determination, taking that section 12 into account. The rules are set out in detail, there are mechanisms to manage such a conflict. It is managed legally, but not humanely. The first way to manage that kind of conflict is through communication between patient and doctor. Conflicts arise almost always because of communication problems, inadequate information and positions that are overly authoritarian. The patient is not given the time needed to understand and accept those decisions.

In Quebec legislation, there are extremely speedy and efficient mechanisms to resolve such conflicts. Problems of that nature do arise.

**Ms Deleury:** Concerning the data that might be available about such conflict resolution, my colleague just referred to section 16 of the Civil Code. That section allows the use of court proceedings in the case when an institution feels that the mandatary is not acting in the best interest of the incapable person and does not seem to carry out that person's will. Under the present legal framework, there have not been many court cases dealing with the rights and powers of the mandatary.

[English]

**The Chairman:** I have a question regarding the ever-increasing cost of drugs. As we move to more in-home care and to more in-home palliative care and hospices, and so on, will there be a problem? Once outside the hospital setting, in most provinces — not in the province of Quebec — drugs are no longer covered by the health care system. Will that be a problem?

**Dr. Latimer:** That is a good question. Many of the medications that we order outside hospital in Ontario are covered, particularly for people over the age of 65. There is private insurance coverage also for those under 65, from employee drug care plans, et cetera. However, there is a group of people who have no extra coverage.

Il faut quand même admettre qu'il y a eu des changements au cours des 10 dernières années. Mon confrère, Me Ménard, pourrait élaborer là-dessus en ce qui a trait à la culture hospitalière.

**M. Ménard:** Il est important de savoir que le pouvoir décisionnel du mandataire au profit d'autrui est balisé dans le droit québécois. Autrement dit, le mandataire ne peut pas décider n'importe quoi. On l'oblige à agir dans l'intérêt de la personne qu'il représente, en tenant compte de ses volontés et en s'assurant que les soins sont bénéfiques, opportuns et que les risques ne sont pas disproportionnés. La loi prévoit que si l'équipe traitante n'agit pas dans l'intérêt de la personne selon le mandataire, on peut s'adresser au tribunal. Au Québec, cela se fait assez régulièrement avec la nouvelle législation. Le nouvel article 16 du Code civil prévoit que le mandataire peut faire tester le bien-fondé de cette décision. Les tribunaux apprécient en tenant compte de cet article 12. On a balisé ces règles, les mécanismes de gestion de ce conflit. On le gère légalement mais pas humainement. La première manière de gérer ces conflits, c'est par la communication du patient et du médecin. Les litiges surgissent presque toujours suite à des problèmes de communication, d'information inadéquate et de positions trop autoritaires. On ne laisse pas le temps au patient de cheminer par rapport à ces décisions.

Dans le contexte du droit québécois, il existe des mécanismes de solution de ces conflits extrêmement rapides et efficaces. Ces problèmes arrivent effectivement.

**Mme Deleury:** Concernant les données que l'on peut avoir sur la résolution de ces conflits, mon confrère vient de faire référence à l'article 16 du Code civil. Ce dernier permet de recourir au système judiciaire dans le cas où l'établissement estime que le mandataire qui représente la personne inapte n'agit pas au meilleur de son intérêt et ne semble pas vouloir respecter ses volontés. Dans le contexte actuel, on n'a pas vu beaucoup de cas devant les tribunaux concernant les droits et les pouvoirs du mandataire.

[Traduction]

**La présidente:** J'ai une question au sujet du coût toujours croissant des médicaments. À mesure qu'on s'orientera de plus en plus vers les soins à domicile et les soins palliatifs à domicile ou en centres hospitaliers de longue durée, aurons-nous des problèmes? À l'extérieur du milieu hospitalier, dans la plupart des provinces — sauf au Québec — les médicaments ne sont pas couverts par le Régime de soins de santé. Est-ce que ce sera un problème?

**Dre Latimer:** C'est une bonne question. Beaucoup des médicaments que nous prescrivons à l'extérieur des hôpitaux en Ontario sont couverts, particulièrement pour les personnes de plus de 65 ans. Il y a aussi des régimes privés pour les personnes de moins de 65 ans, des régimes d'assurance-médicaments pour les employés, par exemple. Il y a toutefois bon nombre de gens qui n'ont pas d'assurance supplémentaire.

Some of the medications are very costly. Some of the opiate-analgesic preparations for pain control are costly, so there will be an issue there. There is already an issue there in Ontario. I am not sure about other provinces, but I think they have the same issue.

The other issue that we know about in Ontario concerns the criteria for ordering certain palliative care medications. A group of physicians in Ontario are about to join together to lobby to have a palliative care formulary of medications that would be freely available for palliative care situations, defining "palliative care" as broadly and as flexibly as we can so that people will have access to the medications they need.

To answer your question, yes, there will be some cost issues and there are some obstacles to ordering some of the medications at the present time.

**The Chairman:** I made that comment because I read a study in the past week that would indicate that if you earn less than \$25,000 a year in this country then you are probably 75 per cent less likely to have a private pharmacare program. On the other hand, if you earn over \$100,000, you are likely to have 100 per cent coverage. There is a gap here.

I want to thank all of you very much for participating in today's forum. All the senators think your presentations were extremely critical and important.

[Translation]

**Ms Vadboncoeur:** When we were asked very recently to take part in this meeting, we were told to limit our comments to chapter 6 which deals with advance directives or agreements, therefore issues that have more to do with civil law. That is the reason why I brought with me experts in the field. I see that our mandate is to study all the recommendations contained in the unanimous 1995 report. The Barreau du Québec is used to making comments on Quebec legislation or federal government legislation. We could study the other recommendations and send you a report because I feel that your hearings will be over by then. I do not know whether this offer is of interest to you. It will depend on your deadlines.

[English]

**The Chairman:** We would be delighted to hear any additional comments that you have. We are trying to table the report on June 6, which would be exactly five years from the date of the original report. We think that is symbolic. It is clear that we believe not nearly enough has been done, and that will be clearly reflected in the report. That is what we want to do. It is a report card to tweak some people into doing a little more.

[Translation]

**Senator Corbin:** You would have to send us your comments on the other recommendations by mid-April.

Certains des médicaments sont très coûteux. Certaines préparations analgésiques opiacées, destinées à soulager la douleur, sont très coûteuses et cela pourrait être un problème. C'en est déjà un en Ontario. Je ne sais pas ce qu'il en est dans les autres provinces, mais je présume que c'est la même chose.

L'autre problème que nous connaissons, en Ontario, se rapporte aux critères relatifs à la prescription de certains médicaments de soins palliatifs. Un groupe de médecins ontariens est en train de s'organiser pour faire des pressions afin qu'un formulaire de médicaments de soins palliatifs soit disponible pour toutes les situations de soins palliatifs, en définissant ces situations de manière aussi large et souple que possible, afin que les gens aient accès aux médicaments dont ils ont besoin.

Pour répondre à votre question, oui, il y aura des questions de coût et il y a des obstacles à la prescription de certains médicaments, pour l'instant.

**La présidente:** J'en ai parlé parce que j'ai lu une étude, la semaine dernière, selon laquelle si vous gagnez moins de 25 000 \$ par an, au Canada, vous avez 75 p. 100 moins de chance d'avoir un régime d'assurance-médicaments privé. Par contre, si vous gagnez plus de 100 000 \$, vous êtes probablement couvert à 100 p. 100. Il y a un écart.

Je vais vous remercier tous infiniment pour votre participation au forum d'aujourd'hui. Tous les sénateurs ont trouvé vos exposés extrêmement importants.

[Français]

**Mme Vadboncoeur:** Quand la demande nous a été faite très récemment de participer à cette séance, on nous a dit de limiter nos commentaires au chapitre 6 concernant les ententes ou les directives préalables, donc un peu plus axés sur le droit civil. C'est la raison pour laquelle je me suis fait accompagner d'experts dans le domaine. Je constate que votre mandat est d'étudier toutes les recommandations du rapport unanime de 1995. Le Barreau du Québec est habitué à intervenir sur la législation du Québec ou du gouvernement fédéral. Il pourrait se pencher sur les autres recommandations et vous envoyer un rapport parce que j'ai l'impression que les audiences seront terminées. Je ne sais pas si l'offre vous intéresse. Cela dépend des délais que vous avez.

[Traduction]

**La présidente:** Nous serons ravis de prendre connaissance de tout autre commentaire que vous pourriez avoir. Nous voulons préparer notre rapport pour le 6 juin, soit exactement cinq ans après la parution du premier rapport. Nous pensons que c'est symbolique. Manifestement, nous ne pensons pas qu'il y a eu suffisamment de progrès, et nous en parlerons clairement dans notre rapport. Voilà ce que nous voulons faire. Nous espérons que les mauvaises notes que nous attribuerons pousseront les intéressés à faire un peu plus d'efforts.

[Français]

**Le sénateur Corbin:** Il faudrait que vous nous envoyiez vos commentaires sur les autres recommandations au plus tard avant la mi-avril.

[English]

**The Chairman:** I think we can deal with them until the first week in May.

[Translation]

**Senator Beaudoin:** I would like to get some comments on the jurisprudence and on a few sections of the Criminal Code dealing with refusal of treatment. We often conclude too quickly that there is no need for legislation. I believe there is always a need for legislation. We have a lot of laws that are not excellent, but we will never have too many excellent laws. I would be very grateful if you could do it by June, it would be very useful to us.

[English]

**The Chairman:** Thank you very much.

The committee adjourned.

[Traduction]

**La présidente:** Je pense que nous pourrons les examiner avant la première semaine de mai.

[Français]

**Le sénateur Beaudoin:** J'aimerais avoir quelques commentaires sur la jurisprudence et quelques articles du Code criminel sur le refus de traitement. On conclut trop vite que l'on n'a pas besoin de législation. Je crois qu'on a toujours besoin d'une bonne législation. Nous avons beaucoup de lois qui ne sont pas excellentes mais nous n'aurons jamais trop de lois excellentes. Je serais très heureux que vous le fassiez, d'ici le mois de juin, cela nous serait très utile.

[Traduction]

**La présidente:** Merci beaucoup.

La séance est levée.

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*From the Catholic Health Association of Canada:*

Sister Annette Noël, Vice-Chair, Board of Directors;

Dr. Elizabeth Latimer, Professor, Department of Family  
Medicine, McMaster University;

Dr. Richard Haughian, President.

*From the Barreau du Québec:*

Ms Suzanne Vadboncoeur, lawyer, Director, Research and  
Legislation Division;

Ms Edith Deleury, Professor, lawyer, Université Laval;

Mr. Jean-Pierre Ménard, lawyer.

*De l'Association catholique canadienne de la santé:*

Soeur Annette Noël, vice-présidente, conseil  
d'administration;

La docteure Elizabeth Latimer, professeure, département de  
médecine familiale, Université McMaster;

Le docteur Richard Haughian, président.

*Du Barreau du Québec:*

Mme Suzanne Vadboncoeur, avocate, directrice, Service de la  
recherche et de la législation;

Mme Edith Deleury, avocate, professeure, Université Laval;

M. Jean-Pierre Ménard, avocat.



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## SENATE OF CANADA

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# Update “Of Life and Death”

# Mise à jour de «De la vie et de la mort»

*Chair:*  
The Honourable SHARON CARSTAIRS

*Présidente:*  
L'honorable SHARON CARSTAIRS

Tuesday, March 28, 2000

Le mardi 28 mars 2000

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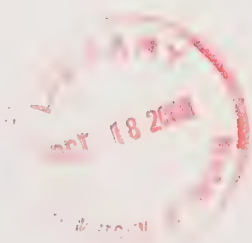
Fascicule n° 8

**Eighth meeting on:**  
Examination of the developments since the tabling in  
June 1995 of the final report of the Special Senate  
Committee on Euthanasia and Assisted Suicide,  
entitled “Of Life and Death”

**Huitième réunion concernant:**  
L'étude des faits nouveaux survenus depuis le dépôt,  
en juin 1995, du rapport final du comité sénatorial  
spécial sur l'euthanasie et l'aide au suicide intitulé:  
«De la vie et de la mort»

WITNESSES:  
(See back cover)

TÉMOINS:  
(Voir à l'endos)



THE SUBCOMMITTEE TO UPDATE  
“OF LIFE AND DEATH”

The Honourable Sharon Carstairs, *Chair*

The Honourable Gérald-A. Beaudoin, *Deputy Chair*

and

The Honourable Senators:

* Boudreau, P.C. (or Hays) Corbin Keon	* Lynch-Staunton (or Kinsella) Roche
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\* *Ex Officio Members*

(Quorum 3)

*Changes in membership of the committee:*

Pursuant to rule 85(4), membership of the committee was amended as follows:

The name of the Honourable Senator Roche was substituted for that of the Honourable Senator Pépin (*March 28, 2000*).

The name of the Honourable Senator Corbin was substituted for that of the Honourable Senator Kirby (*March 28, 2000*).

The name of the Honourable Senator Kirby was substituted for that of the Honourable Senator Corbin (*March 22, 2000*).

LE SOUS-COMITÉ DE MISE À JOUR DE  
«DE LA VIE ET DE LA MORT»

*Présidente:* L'honorable Sharon Carstairs

*Vice-président:* L'honorable Gérald-A. Beaudoin

et

Les honorables sénateurs:

* Boudreau, c.p. (ou Hays) Corbin Keon	* Lynch-Staunton (ou Kinsella) Roche
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\* *Membres d'office*

(Quorum 3)

*Modifications de la composition du comité:*

Conformément à l'article 85(4) du Règlement, la liste des membres du comité est modifiée, ainsi qu'il suit:

Le nom de l'honorable sénateur Roche est substitué à celui de l'honorable sénateur Pépin (*le 28 mars 2000*).

Le nom de l'honorable sénateur Corbin est substitué à celui de l'honorable sénateur Kirby (*le 28 mars 2000*).

Le nom de l'honorable sénateur Kirby est substitué à celui de l'honorable sénateur Corbin (*le 22 mars 2000*).

**MINUTES OF PROCEEDINGS**

OTTAWA, Tuesday, March 28, 2000

(10)

[English]

The Subcommittee to update "Of Life and Death" met this day in room 257, East Block, at 9:15 a.m., the Honourable Sharon Carstairs, Chair, presiding.

*Members of the subcommittee present:* The Honourable Senators Beaudoin, Carstairs, Corbin, and Roche (4).

*In attendance:* Mollie Dunsmuir and Nancy Miller-Chénier, Research Officers, Research Branch, Library of Parliament.

Pursuant to its Order of Reference adopted in the Standing Senate Committee on Social Affairs, Science and Technology on Monday, November 29, 1999, the subcommittee continued its examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death". (*For full text of Order of Reference please refer to Issue No. 1.*)

**WITNESSES:**

*Dr. Neil MacDonald, Centre for Bioethics, Clinical Research Institute of Montreal.*

*Professor Brian Mishara, Department of Psychology, Université du Québec à Montréal.*

*From the Office of the Chief Coroner of Ontario:*

Dr. James G. Young, Chief Coroner.

*From the Medical Research Council of Canada:*

Dr. Henry Friesen, President.

*Mr. Russel Ogden.*

The Chair made an opening statement.

Dr. Neil MacDonald made a slide presentation and answered questions.

Prof. Brian Mishara, Dr. James G. Young, Dr. Henry Friesen and Russel Ogden each made statements and answered questions.

At 11:50 a.m., the subcommittee proceeded *in camera* to consider future business.

It was agreed that all decisions taken by the subcommittee during the *in camera* portion of this meeting be included in today's printed Minutes of Proceedings.

It was moved by the Honourable Senator Corbin — That a transcript be made of the *in camera* meeting scheduled for Tuesday, April 11, 2000, for the use of the subcommittee researchers and members of the subcommittee only and that all copies of the transcript be destroyed upon tabling of the final report.

After debate, it was agreed.

**PROCÈS-VERBAL**

OTTAWA, le mardi 28 mars 2000

(10)

[Traduction]

Le sous-comité de mise à jour de «De la vie et de la mort» se réunit aujourd'hui, à 9 h 15, dans la pièce 257 de l'édifice de l'Est, sous la présidence de l'honorable Sharon Carstairs (*présidente*).

*Membres du sous-comité présents:* Les honorables sénateurs Beaudoin, Carstairs, Corbin et Roche (4).

*Également présentes:* Mollie Dunsmuir et Nancy Miller-Chénier, attachées de recherche, Direction de la recherche parlementaire, Bibliothèque du Parlement.

Conformément à l'ordre de renvoi adopté par le comité sénatorial permanent des affaires sociales, des sciences et de la technologie du lundi 29 novembre 1999, le sous-comité poursuit son étude des faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort». (*Pour le texte intégral de l'ordre de renvoi, voir le fascicule n° 1.*)

**TÉMOINS:**

*Dr. Neil MacDonald, Centre de bioéthique, Institut de recherche clinique de Montréal.*

*Professeur Brian Mishara, Département de psychologie, Université du Québec à Montréal.*

*Du Bureau du coroner en chef de l'Ontario:*

Dr. James G. Young, coroner en chef.

*Du Conseil de recherches médicales du Canada:*

Dr. Henry Friesen, président.

*M. Russel Ogden.*

La présidente faite une déclaration.

Le Dr. Neil MacDonald fait un exposé à l'aide de diapositives et répond aux questions.

M. Brian Mishara, le Dr. Henry Friesen et Russel Ogden font à tour de rôle une déclaration et répondent aux questions.

A 11 h 50, le sous-comité poursuit ses travaux à huis clos pour examiner ses travaux futurs.

Il est convenu que toutes les décisions prises par le sous-comité pendant la portion à huis clos de cette réunion seront jointes aux délibérations imprimées de la séance d'aujourd'hui.

Il est proposé par l'honorable sénateur Corbin — Qu'une transcription soit faite de la réunion à huis clos prévue pour le mardi 11 avril 2000 aux fins d'utilisation par les attachés de recherche et les membres du sous-comité seulement et que tous les exemplaires de la transcription soient détruits au moment du dépôt du rapport final.

Après discussion, la motion est adoptée.



At 11:58 a.m., the subcommittee adjourned to the call of the Chair.

*ATTEST:*

À 11 h 58, le sous-comité suspend ses travaux jusqu'à nouvelle convocation de la présidence.

*ATTESTÉ:*

*La greffière du comité,*

Heather Lank

*Clerk of the Subcommittee*

## EVIDENCE

OTTAWA, Tuesday, March 28, 2000

The Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 9:15 a.m. to examine the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death."

**Senator Sharon Carstairs** (*Chairman*) in the Chair.

[*English*]

**The Chairman:** Honourable senators, today is our eighth day of hearings under our mandate to update the unanimous recommendations contained in the 1995 report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death".

I would remind honourable senators and witnesses that this committee is not reopening the debate on euthanasia and assisted suicide. It is dealing strictly with the areas of the report where the original committee made unanimous recommendations. I would ask that everyone bear this in mind.

We have two panels today. On our first panel we have one guest, Dr. Neil MacDonald from the Centre for Bioethics, Clinical Research Institute of Montreal. As a reminder to both Senator Roche and Senator Beaudoin, I will point out that Dr. MacDonald presented to our first committee. The focus of his testimony at that time concerned the training of physicians. Specifically, we have invited him back today to talk about the training of physicians in pain management and palliative control. Dr. MacDonald, you are most welcome once again.

**Dr. Neil MacDonald, Centre for Bioethics, Clinical Research Institute of Montreal:** I am pleased to meet with you once again, five years after I first appeared before the committee on euthanasia and physician-assisted suicide. I am a palliative care physician. I also work in a bioethics program, and I am a former cancer centre administrator. I used to be the director of the provincial cancer program and the Cross Cancer Institute in Edmonton, Alberta, some years ago.

Since we are talking about education, I will limit my comments to education in palliative care. We could talk about the general education of professionals, the specific education of people training in palliative care and, very importantly, the education of patients, families, and the community in palliative care. I will limit my comments to the training of medical students and residents in medical schools, but I would be pleased to comment or answer any questions on other areas of palliative care education, if time allows.

Approximately five years ago, I presented information in which I pointed out that the training of doctors in palliative medicine was clearly unsatisfactory. Five years and five months later I am back, and I would like to be able to tell you that the situation has changed positively and dramatically, but it has not. It still remains,

## TÉMOIGNAGES

OTTAWA, le mardi 28 mars 2000

Le sous-comité de mise à jour de «De la vie et de la mort» du comité sénatorial permanent des affaires sociales, des sciences et de la technologie se réunit aujourd'hui à 9 h 15 en vue d'étudier les faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort».

**Le sénateur Sharon Carstairs:** (*présidente*) occupe le fauteuil.

[*Traduction*]

**La présidente:** Honorables sénateurs, aujourd'hui marque le huitième jour des audiences tenues dans le cadre de notre mandat visant à mettre à jour les recommandations du rapport de 1995 sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort».

Je vous rappelle, à vous et à nos témoins, que le sous-comité ne reprend pas le débat sur l'aide au suicide et l'euthanasie. Il se concentre uniquement sur les parties du rapport où le comité initial avait fait des recommandations unanimes. Je vous demanderais de ne pas l'oublier.

Nous entendrons aujourd'hui deux groupes de témoins. Nous entendrons d'abord le Dr Neil MacDonald, du Centre de bioéthique de l'Institut de recherche clinique de Montréal. Je rappelle au sénateur Roche et au sénateur Beaudoin que le Dr MacDonald a déjà comparu devant notre premier comité. À cette époque, son témoignage portait sur la formation des médecins. Nous l'avons invité à comparaître de nouveau aujourd'hui pour parler plus précisément de la formation des médecins dans le domaine de la gestion de la douleur et des soins palliatifs. Bienvenue de nouveau, docteur MacDonald.

**Dr Neil MacDonald, Centre de bioéthique, Institut de recherche clinique de Montréal:** C'est avec plaisir que je viens vous rencontrer de nouveau, cinq ans après ma première comparution devant le comité sur l'euthanasie et l'aide au suicide. J'exerce la médecine palliative. Je travaille également dans un programme de bioéthique et je suis un ancien administrateur du centre d'oncologie. J'ai déjà été directeur du programme provincial d'oncologie et du Cross Cancer Institute d'Edmonton, en Alberta, il y a quelques années.

Puisque nous parlons d'enseignement, mes observations porteront uniquement sur l'enseignement des soins palliatifs. Je pourrais vous parler de l'enseignement général qui est dispensé aux professionnels, de la formation en soins palliatifs et, plus encore, de la formation offerte aux patients, aux familles et aux collectivités en soins palliatifs. Mes observations se limiteront toutefois à la formation des étudiants en médecine et des résidents des facultés de médecine. Je suis toutefois prêt à répondre à toutes vos questions sur les autres aspects de l'enseignement des soins palliatifs, si le temps le permet.

Il y a cinq ans environ, j'ai déclaré que la formation des médecins dans le domaine de la médecine palliative était clairement insatisfaisante. Cinq ans et cinq mois plus tard, j'aimerais bien pouvoir vous dire qu'il y a eu des améliorations spectaculaires, mais ce n'est pas le cas. La situation demeure

by and large, unsatisfactory, although there are a few areas where it is clear that there has been some improvement.

Not only to offer you rhetoric, but also to give you a bit of evidence on the statement I make, is the slide on end-of-life care. This is a review of 50 major medical textbooks that are studied by our residents and students. The people doing the study reviewed the chapters on common causes of death. They found, as you will note, that in more than half of them there was no information that was at all helpful to people reading these textbooks on dying from cancer, dying from congestive heart failure, and so on. It was as if, in the medical textbooks, people do not die.

You will also note that in both the worst and the best textbooks, geriatrics and family practice were rated slightly higher, but the worst textbooks were those on cancer and AIDS, two causes of chronic illness and death where suffering is manifest.

About the same time — that is, 1999 or late 1998 — there was an interesting study of the people who run the clerkships in internal medicine in our hospitals through, primarily, American experience. In this study, they were asked what were the important, core topics that had to be taught to the residents and the students. End of life did not appear on the radar screen at all. At the top were the important but conventional things that we teach, such as hypertension, management of coronary artery disease, and management of chronic pulmonary disease. Cancer pain was not included, and neither was a specific emphasis on end of life.

That intrigued me and a number of my colleagues. You may recall that I gave you some data previously from the Canadian Palliative Care Education Group, which has representatives in each of our schools to observe the hours of teaching in palliative care. We have maintained regular surveys, and in 1999 we started asking for the medical students' opinions on their experiences and the calibre of our teaching in palliative care.

I am showing now a graph of survey results from the University of Alberta and from McGill. Both these schools are, by the nature of their research programs and teaching hours, arguably at the top of our Canadian medical schools in palliative care teaching.

Our students were asked, at the end of the day, for their thoughts on teaching in hypertension and breast cancer. We postulated that the results would be extremely good. We assigned a "1" as very good and a "4" as very bad. Their overall experience, as expressed here, was good. Looking at the palliative care experiences, though, the students did not think the teaching was nearly as good.

Regarding management of cancer pain, only 3 of the combined group of 110 students — representing about 50 per cent of the overall class — thought that their overall experience and the teaching were excellent. Two thought the experience was very

insatisfaisante dans une grande mesure, même si dans certains domaines il y a eu quelques améliorations.

Je ne veux pas me limiter à la théorie, je veux aussi vous donner des exemples de ce que je dis, comme on peut le voir sur le transparent sur les soins en fin de vie. On a fait un examen de 50 grands manuels médicaux qu'étudient nos étudiants et nos résidents. Les gens qui ont réalisé cette étude ont examiné les chapitres sur les principales causes de décès. Comme vous le remarquerez, ils ont constaté que dans plus de la moitié de ces manuels on ne trouvait aucun renseignement utile pour les étudiants sur les patients qui meurent de cancer, de défaillance cardiaque, et cetera. On dirait presque que, dans les manuels de médecine, les gens ne meurent pas.

Vous remarquerez également que tant dans les meilleurs manuels que dans les pires la cote était un peu plus élevée en gériatrie et en médecine familiale, mais que les pires manuels étaient ceux qui portaient sur le cancer et le sida, deux maladies chroniques mortelles dans lesquelles la souffrance est évidente.

Parallèlement — c'est-à-dire à la fin de 1998 ou en 1999 — on a fait une étude intéressante sur les gens qui dirigent les stages des internes dans nos hôpitaux, plus particulièrement dans les hôpitaux américains. Dans le cadre de cette étude, on a demandé quels étaient les sujets les plus importants à enseigner aux résidents et aux étudiants. Aucun des répondants n'a parlé des soins en fin de vie. En tête de liste, on trouvait des sujets qui sont traditionnellement enseignés, entre autres l'hypertension, la gestion des maladies coronariennes et la gestion des maladies pulmonaires chroniques. Personne n'a parlé de la souffrance liée au cancer non plus que des soins en fin de vie.

Cela nous a intrigués, un certain nombre de mes collègues et moi. Vous vous souviendrez peut-être que je vous avais fourni des données provenant du Canadian Palliative Care Education Group. Ce groupe a des représentants dans chacune de nos facultés. Ils sont chargés d'observer le nombre d'heures d'enseignement des soins palliatifs. Nous avons fait des enquêtes régulièrement, et en 1999 nous avons commencé à demander aux étudiants en médecine ce qu'ils pensaient de leur expérience et du calibre de notre enseignement des soins palliatifs.

Voici un tableau illustrant les résultats d'une enquête menée à l'Université de l'Alberta et à McGill. Ces deux facultés sont probablement les meilleures facultés de médecine canadiennes pour l'enseignement des soins palliatifs, en raison de la nature de leurs programmes de recherche et de leurs heures d'enseignement.

On a demandé à nos étudiants ce qu'ils pensaient de l'enseignement relatif à l'hypertension et au cancer du sein. Nous avions prévu que les résultats de ces questions seraient extrêmement positifs. Une cote «1» signifie très bien et une cote «4» très mauvais. D'une façon générale, les étudiants ont estimé que l'expérience était bonne. Dans le cas des soins palliatifs, par contre, les étudiants ont jugé que l'enseignement était loin d'être aussi bon.

Au chapitre de la gestion de la douleur provoquée par le cancer, seulement trois des 110 groupes combinés d'étudiants — qui représentaient environ 50 p. 100 de toute la classe — jugeaient que tant leur expérience que l'enseignement avaient été excellents.



good, but the majority, 49 plus 7, thought the experience was either not very good or, indeed, very poor.

Contrast that with the teaching in hypertension, which brought an entirely different result. The majority of these students thought their experience was either excellent or very good.

We have a paradox here. Any time you stand up in medical school to teach, you get a rating. I know that the ratings at McGill for lecture and small group presentations are excellent. I have worked at the University of Alberta and I know the ratings there are excellent. The students listen to us lecture and they say that the teaching is very good, but, at the end of four years, they say that the overall experience is unsatisfactory.

This paradox goes back to my earlier statement about what happens on the wards. Research tells us that students and residents learn primarily from clinical experience with patients, as directed by role models on the wards. We do not have role models on our wards to teach proper end-of-life care. We can lecture, but it is to relatively modest effect without those role models who are, on a day-to-day basis, demonstrating excellence in care to our students.

Factors limiting pain control were the subject of a recent study amongst oncologists and palliative care doctors in the Province of Quebec. On the scale used for this study, "1" is excellent and "5" is poor. In the opinions of these physicians, the big problem in managing cancer pain does not lie with access to drugs, but with physician reluctance to use opioids and patient misunderstanding about the use of pain medication. The problem also lies with education. They say that our problem in Canada is not access to proper therapy for pain management, but rather teaching it and applying it well.

I have listed for you the common educational aims to which, if you were to ask 16 Canadian deans, they would likely all subscribe. The list is extracted from a review of the literature in medical school education. We want to teach in the home and community; to shift from the institution and to teach whole-person care. We must learn to work in teams, because that is the way modern medical care is conducted. We must improve communication skills and, of course, we want to think of medical issues in ethical terms. These are common aims not just for palliative care, but for medical education in general.

How do we spend our time in medical schools? I have noted that in our hospitals, I often see our residents and interns or students wearing operating-room green. I thought in part that might be a fashion statement, but it is more than that. In our survey, we compared the time that our students spend in operating theatres with the actual time they spend in the community or in

Deux trouvaient que l'expérience était bonne, mais la majorité, 49 plus 7, trouvaient que l'expérience avait été plutôt médiocre, sinon mauvaise.

Comparativement, l'enseignement relatif à l'hypertension a permis d'obtenir des résultats entièrement différents. D'après la majorité des étudiants, l'expérience avait été excellente ou très bonne.

Nous nous trouvons ici devant un paradoxe. Tous les professeurs qui enseignent dans les facultés de médecine sont évalués. À McGill, je sais que les cotes attribuées aux cours magistraux et aux présentations en petits groupes sont excellentes. J'ai travaillé également à l'Université de l'Alberta et je sais que les cotes y sont également excellentes. Les étudiants écoutent nos cours magistraux et trouvent que l'enseignement est très bon. Mais au bout de quatre ans ils nous disent qu'en général leur expérience est insatisfaisante.

Le paradoxe revient à ce que je disais dans mon témoignage précédent sur ce qui se fait dans les services hospitaliers. D'après les recherches, c'est surtout dans l'expérience clinique auprès des patients, sous la direction de modèles dans les services hospitaliers, que les étudiants et les résidents font leur apprentissage. Mais dans les services hospitaliers il n'existe pas de modèles pour enseigner comment offrir de bons soins en fin de vie. Les cours magistraux ne suffisent pas. Leur efficacité est limitée si nous n'avons pas de modèles qui puissent tous les jours faire preuve d'excellence devant nos étudiants.

Les oncologues et les médecins de médecine palliative du Québec ont récemment effectué une étude sur les facteurs qui limitent le contrôle de la douleur. Dans ce cas-ci, la cote «1» correspond à excellent et «5» à médiocre. D'après ces médecins, le grand problème dans la gestion de la douleur liée au cancer ne vient pas de l'accès aux médicaments, mais plutôt de la réticence des médecins à utiliser des opioïdes et à l'incompréhension des patients quant à l'utilisation des médicaments contre la douleur. Le problème vient également de l'enseignement. D'après ces médecins, le problème au Canada, ce n'est pas l'accès à de bons soins contre la douleur, mais plutôt l'enseignement et l'application de la gestion de la douleur.

Voici une liste des principaux objectifs d'enseignement auxquels souscriraient probablement les 16 doyens des facultés canadiennes. Cette liste est tirée d'un examen des ouvrages sur l'enseignement dans les facultés de médecine. On veut enseigner les soins à domicile et dans les collectivités, offrir des soins ailleurs qu'en établissement et enseigner les soins holistiques. Nous devons apprendre à travailler en équipe, car c'est de cette façon que sont offerts les soins médicaux à notre époque. Nous devons améliorer les compétences en communication, et, bien sûr, situer les questions médicales dans un cadre déontologique. Ce sont des objectifs qui ne touchent pas seulement les soins palliatifs, mais aussi l'enseignement de la médecine en général.

À quoi est consacré le temps dans les facultés de médecine? J'ai remarqué que dans nos hôpitaux je vois souvent nos résidents, nos internes ou nos étudiants porter l'habit des salles d'opération. J'ai pensé que c'était peut-être une question de mode, en partie, mais c'est plus que cela. Dans notre enquête, nous avons comparé le temps que nos étudiants passent dans les salles d'opération au

interdisciplinary teaching situations. An exceptional discrepancy was found.

We asked the students whether they wanted more palliative care teaching and 85 per cent said yes. They were at some pains to tell us that they did not want us to take them out of the operating theatres necessarily, but in both these schools, they were able to suggest some selected areas where time could be assigned for clinical palliative care teaching.

It is a common complaint in medical schools that there is so much new information and no room in the curriculum. This information suggests room can be found by moving priorities around. Palliative medicine is not a special-interest group. The teaching of palliative medicine provides an excellent laboratory, if you wish, for the general principles of medical education that people espouse.

Some things have improved. Five years ago, I said our group was updating the Canadian palliative medicine curriculum, which we did. We published that in a book called *Palliative Medicine* containing contributions from representatives of 12 of our 16 medical schools. We arranged, through a pharmaceutical company grant, to give copies of this book, which is printed by Oxford Press at cost, to the graduating class of each of our Canadian medical schools in one year. A second year is now under way, and the book is in the process of being translated into French. It will be distributed to our francophone schools in the next academic year.

This is an excellent example of people working together. I am very proud to note that this book is sold commercially around the world and has been a success. We have been asked by Oxford Press to produce a second edition because of its sales. I am proud to report that the people who wrote for this textbook have donated all of their royalties to a Canadian palliative care education fund.

Our next slides show something important that comes, in part, from the initiatives of a number of doctors, including an Ottawa doctor, Dr. John Seely, former dean at the University of Ottawa. These doctors have been contacting the LCME, or the Liaison Committee for Medical Education, which is the group that reviews our medical schools in Canada and the United States, to try to increase that agency's expectations. This year, they have included for first time this statement: "Clinical education must include experience in palliative care management and end-of-life care." The rhetoric is in place, and now we must see how we will proceed.

There is an interesting report published by the Institute of Medicine of the United States Academy of Sciences. If the senators do not have a copy, I strongly recommend you obtain one. I can tell you how to get it from the institute of medicine. This is a review of the status of palliative and end-of-life care in the United States, printed two years ago, and entitled, "Approaching Death." The report uniformly concludes that care was clearly

temps réel qu'ils passent dans la collectivité ou dans des cadres d'enseignement interdisciplinaire. Nous avons constaté un écart énorme.

Nous avons demandé aux étudiants s'ils aimeraient avoir davantage de cours sur les soins palliatifs, et 85 p. 100 d'entre eux ont répondu oui. Ils se sont empressés d'ajouter qu'ils ne souhaitent pas nécessairement qu'on les retirent des salles d'opération mais, dans ces deux facultés, les étudiants ont été en mesure de suggérer des plages horaires qui pourraient être réservées à l'enseignement des soins palliatifs cliniques.

Les étudiants des facultés de médecine se plaignent régulièrement de l'abondance d'information à assimiler et du manque de temps à l'horaire des cours. Cette information donne à croire qu'il aurait moyen de trouver le temps nécessaire en réaménageant les priorités. Les soins palliatifs n'intéressent pas que des groupes d'intérêts particuliers. L'enseignement de la médecine palliative est un excellent laboratoire, pour ainsi dire, qui se prête à l'enseignement des principes généraux d'éducation médicale auxquels croient les gens.

Il y a eu certaines améliorations. Il y a cinq ans, j'ai dit que notre groupe mettait à jour le programme d'enseignement de la médecine palliative, et nous l'avons fait. Nous avons publié un ouvrage intitulé: *Palliative Medicine* auquel ont contribué les représentants de 12 de nos 16 facultés de médecine. Grâce à la subvention d'une société pharmaceutique, nous avons pu faire don une année de cet ouvrage, imprimé au prix coûtant par Oxford Press, aux diplômés de chacune de nos facultés de médecine. Nous pourrions faire la même chose une deuxième année, et la version française de l'ouvrage est en cours. L'ouvrage sera distribué dans nos facultés francophones pour la prochaine année universitaire.

C'est là un excellent exemple de ce que l'on peut faire quand on travaille de concert. Je suis très fier de signaler que cet ouvrage est en vente partout dans le monde et a été très bien reçu. En raison de ce succès, Oxford Press nous a demandé de préparer une deuxième édition. Je suis également fier de dire que ceux qui ont contribué à cet ouvrage ont fait don de toutes leurs redevances à un fonds canadien pour l'éducation en médecine palliative.

Les acétates suivantes illustrent une initiative importante due, en partie à certains médecins, dont un d'Ottawa, le Dr John Seely, ancien doyen de l'Université d'Ottawa. Ces médecins ont communiqué avec le comité de liaison sur l'éducation médicale (CLEM), chargé de l'évaluation des facultés de médecine au Canada et aux États-Unis, dans le but de relever les attentes de cet organisme. Pour la première fois cette année, ils ont dit: «L'enseignement clinique doit inclure une expérience en gestion des soins palliatifs et en soins aux personnes en fin de vie.» Les énoncés de mission sont en place, et nous attendons de voir quels seront les résultats.

L'Institute of Medicine de la United States Academy of Sciences a publié un rapport très intéressant. Si les sénateurs n'en ont pas d'exemplaire, je leur recommande fortement d'en obtenir un. Je peux vous expliquer comment l'obtenir de l'Institute of Medicine. Il s'agit d'une analyse des soins palliatifs et des soins aux personnes en fin de vie offerts aux États-Unis, imprimée il y a deux ans, et qui s'intitule: «Approaching Death». Le rapport



inadequate. It contains a number of first-rate recommendations that I will address later. It is an excellent summary document on palliative care and end of life in the United States.

This is my question: Are we looking at inequalities in education, or inequities? An inequality is something we cannot address; it is an empirical difference. I am older than most of the people sitting behind me, and although I would like to be younger, I cannot be. That is an inequality and I cannot do anything about it. An inequity, though, is a difference that is unfair or unjust, the dimensions of which can be changed. I regard the level of interest in palliative care education and palliative care research in our medical schools as an inequity, because it is possible to recognize the differences and do something about them. It takes willpower and a setting of priorities.

How do we do that? I call your attention to a very interesting book by a sociologist named Everett Rogers. He talks about how ideas are diffused through society, how they gain acceptance, how you can have something promising like a better keyboard for computers that never gains acceptance, and how you can teach people in a variety of ways to accept an idea. This slide is a summary of his ideas, very briefly expressed. I call your attention to the orange arrow. Critically, he makes the point that you can come up with good ideas, but unless you can convince those in charge, the opinion leaders, the people who change the curricula, the people who set the exams, the people who audit process, then these good ideas will not be accepted, even with community pressure, senatorial pressure, and acceptance and completion of a set of information by palliative care people.

In five years, we have seen a great deal of information and good teaching material in palliative care, but I have given you some evidence that it has not been satisfactory.

In palliative medicine and end-of-life care, we have seen adaptation of new concepts and the development of a specific body of knowledge. Persuasion through role models is a critical factor that must be achieved. Decision-making by influential opinion leaders must occur. We then need implementation, ensuring that we have appropriate audit and examination content and assessment of what we are doing in end-of-life care. We are clearly still at points 1 and 2 on the adaptation of a new concept.

I would be remiss if I did not mention one other area of improvement, although I will not talk about this formally. We introduced for the first time, in July, a residency training program for palliative care that is sanctioned by the royal college. I understand that probably about eight of our sixteen schools will participate in the first year. We are not certain about the total number of residents, but it will probably range between 10 and 20. This is a start. However, this is a one-year fellowship. This will not train people in research or in education. We do not have support for that kind of critical faculty establishment grant that is needed in all of our Canadian schools.

conclut qu'en règle générale les soins offerts étaient nettement insuffisants. Ce rapport renferme un certain nombre d'excellentes recommandations sur lesquelles je reviendrai un peu plus tard. C'est un excellent document d'analyse sur les soins palliatifs et les soins aux personnes en fin de vie aux États-Unis.

Voici ma question: devons-nous parler d'inégalités ou d'iniquités dans l'enseignement? Nous ne pouvons pas agir contre une inégalité; c'est une différence empirique. Je suis plus âgé que la plupart des personnes assises derrière moi, et même si j'aimerais être plus jeune, je ne le peux pas. C'est là une inégalité, et je n'y peux rien. Cependant, une iniquité est une différence injuste que l'on peut corriger. J'estime que le degré d'intérêt porté à l'enseignement des soins palliatifs et à la recherche sur les soins palliatifs dans nos facultés de médecine est une iniquité, car il est possible de constater les différences et de tenter de les corriger. Il faut pour cela la volonté d'agir et les bonnes priorités.

Comment pouvons-nous le faire? Je vous recommande la lecture d'un livre très intéressant du sociologue Everett Rogers. Il parle de la diffusion des idées dans la société, de la façon dont elles viennent à être acceptées, de la façon dont un meilleur clavier d'ordinateur est néanmoins rejeté par les consommateurs et des façons d'enseigner aux gens à accepter les idées nouvelles. Cet acétate est un synopsis de ses idées exprimées de façon très schématique. Je vous signale la flèche orange. Il dit essentiellement que l'on peut avoir d'excellentes idées, mais qu'elles ne seront jamais acceptées malgré les pressions de la collectivité, des sénateurs et l'élaboration d'une trousse d'information complète par les praticiens dans le domaine des soins palliatifs si l'on ne réussit pas à convaincre les décideurs, ceux qui orientent l'opinion publique, ceux qui élaborent les programmes d'études, ceux qui régissent les examens, ceux qui évaluent les résultats.

En cinq ans, j'ai vu qu'il y avait beaucoup d'informations et de documents pédagogiques sur les soins palliatifs, mais je vous ai démontré que ce n'était pas suffisant.

Dans les domaines de la médecine palliative et des soins en fin de vie, nous avons constaté que de nouveaux concepts ont été adaptés et qu'un corpus de connaissances s'est élaboré. Il est essentiel de mettre en place un régime de persuasion par des modèles. Des décisions doivent être prises par des leaders capables d'influer sur l'opinion publique. Il faut ensuite mettre tout cela en oeuvre et voir à ce qu'il y ait des évaluations suffisantes de ce qui se fait dans le domaine des soins en fin de vie. De toute évidence, nous en sommes encore aux deux premiers éléments de l'adaptation d'un nouveau concept.

Je m'en voudrais de ne pas mentionner une autre amélioration, bien que je n'en parlerai pas de façon officielle. Pour la première fois, en juillet, nous avons mis sur pied un programme de formation en soins palliatifs à l'intention des résidents. Ce programme est approuvé par le collège royal. Je crois savoir que dès la première année huit des seize facultés offriront ce programme. Nous ne sommes pas certains du nombre total de résidents, mais il y en aura probablement de dix à vingt. C'est un début. Il s'agit toutefois d'un programme d'un an. Ce programme n'offrira pas de formation en recherche ou en enseignement. Nous n'avons pas de soutien pour ce qui est des subventions dont toutes nos facultés canadiennes ont grand besoin.



I call your attention to a very positive movement that has major connotations for Canada, and that is that the United States, after lagging behind us, is getting its act together. This overhead shows core principles of end-of-life care that come from a document from the Milbank Foundation and the hard work of Kathy Foley and Christine Cassel in the United States. They established these core principles and distributed them to the leading medical associations in the United States. If we had these core principles in place, and were teaching them, we would be in pretty good shape in Canada.

This overhead shows a summary of all of the associations that Dr. Cassel and Dr. Foley, working with the heads, were able to bring together to endorse those core principles. Such a movement, to my knowledge, has not occurred in Canada, and it is very important that it does. We are seeing a massive increase in training opportunities and in research funding. The National Institutes of Health in the United States, for example, have put forward a specific request for research in palliative care and have offered support. That is good, because in medical education the borders are transparent. However, it is not so good, inasmuch as, if we remain inadequate, we will lose very good people to the United States. I call your attention to the fact that a very important individual in the University of Toronto program and the head of the program at the University of Alberta have recently moved to the United States. The opportunities there are now becoming manifest. If we do not follow along in both education and research, then we will become an educational colony in this area, and that is an unsatisfactory situation.

I would like to come back in five years and be able to say that we have moved from rhetoric to tangible activity. Tangible activity consists of such things as providing venues for bringing the medical societies together to endorse end-of-life care principles, and where we can ask our deans and our department heads and our medical schools what they intend to do about end-of-life care, how they intend to meet the challenge from the United States, and how they will produce the capacity to train people in education and research to forward the critical work that must be done in this area.

**The Chairman:** I was hoping that you would bring us better news than you were able to bring this morning, but I was aware that not as much progress has taken place in the last five years as we had hoped.

**Senator Beaudoin:** You focus on the educational aspect of palliative care, where not much progress has been made. What about the provinces? They have something to do with this as well. We have a certain responsibility in this field, but so do they. What do you suggest for them? It is a divided field.

**Dr. MacDonald:** This takes us outside of education specifically. A number of the provinces, and you will probably know more about this than I do, have specific initiatives in palliative care. They have introduced some interesting programs in Ontario, amongst others, to train physicians in the field — to come back and obtain some palliative care training. They also have provided

Je vous signale un élément très positif qui a des connotations importantes pour le Canada; les États-Unis, après avoir accusé un retard par rapport à nous, sont en train de se prendre en main. Ce transparent montre les principes essentiels des soins en fin de vie tirés d'un document de la Milbank Foundation et des travaux de Kathy Foley et Christine Cassel, aux États-Unis. Ces principes essentiels ont été élaborés et transmis aux principales associations médicales américaines. Si nous adoptions ces principes essentiels et que nous les enseignions, ce serait un progrès au Canada.

Voici, en résumé, la liste de toutes les associations que le Dr Cassel et le Dr Foley, en collaboration avec leurs dirigeants, ont pu amener à adopter ces principes essentiels. À ma connaissance, rien ne s'est fait dans ce sens au Canada, et il est important que cela se produise. Nous constatons une augmentation massive des possibilités de formation et du financement de la recherche. Aux États-Unis, par exemple, les National Institutes of Health ont expressément demandé que soient effectuées des recherches en soins palliatifs et ont offert un soutien à cette recherche. C'est bien, parce que dans l'enseignement de la médecine il n'existe pas de frontière. Par contre, ce qui est moins bien, c'est que si nous continuons de ne pas être à la hauteur, d'excellents éléments s'en iront aux États-Unis. Je vous signale qu'une personne très importante du programme de l'Université de Toronto et le chef du programme à l'Université de l'Alberta ont récemment déménagé aux États-Unis. On constate qu'il y a là-bas de plus en plus de possibilités. Si nous tirons de l'arrière dans l'enseignement et la recherche, nous deviendrons une colonie en matière d'éducation, et ce n'est pas acceptable.

Dans cinq ans, j'aimerais pouvoir revenir vous dire que nous sommes passés de la théorie à la pratique. La pratique, c'est par exemple offrir aux sociétés médicales des avenues leur permettant d'adopter les principes des soins en fin de vie, de demander aux doyens et aux chefs des départements et des facultés de médecine ce qu'ils entendent faire au sujet des soins en fin de vie, comment ils ont l'intention de relever le défi américain et comment ils mettront en place les ressources nécessaires pour former les gens à l'enseignement et à la recherche pour faire progresser les travaux essentiels qui sont nécessaires.

**La présidente:** J'espérais que vous pourriez nous donner de meilleures nouvelles, mais je savais qu'il n'y avait pas eu au cours des cinq dernières années autant de progrès que nous l'aurions souhaité.

**Le sénateur Beaudoin:** Vous parlez surtout de l'enseignement des soins palliatifs, un domaine où il n'y a pas eu beaucoup de progrès. Qu'en est-il des provinces? Elles ont également été actives dans ce domaine. C'est une question qui relève de notre compétence, dans une certaine mesure, mais de la leur aussi. Que proposez-vous qu'elles fassent? C'est un domaine de compétence partagée.

**Dr. MacDonald:** Cela nous écarte de l'enseignement. Dans un certain nombre de provinces, et vous êtes peut-être plus au courant que moi, il existe des initiatives en soins palliatifs. En Ontario, on a mis sur pied des programmes intéressants, entre autres pour former des médecins dans ce domaine — pour les ramener sur les bancs d'école et leur donner une formation en soins palliatifs.

a more credible arrangement for funding for palliative care physicians, because it does not lend itself well to fee for service. Taking the time to analyze the difficult problems that patients and families have and to provide counselling and psychosocial input does not lend itself to a fee-for-service arrangement. It is not like a chest X-ray. There are some initiatives that vary from place to place.

Nevertheless, I want to concentrate on the medical schools, and I want to concentrate on the heads of our national societies. It is important for a community group, for our Senate, to take the lead in meet with the heads of our national groups, the people who are in charge of the overall educational process in our medical schools, and the people who run the medical councils of Canada. You could meet with the royal college and the college of family physicians to see whether they concur that there are inequities in the teaching in our medical schools, to see if they would buy into some core principles, and then to see what they can do to take matters forward. I think that is done at a national level within the schools and does not depend uniquely upon provincial health care input. They can help a great deal by setting up good situations in which palliative physicians can practise, and perhaps assist in continuing education. Medical schools interact on a national as well as a provincial level.

**Senator Beaudoin:** Do you think that we need to change the legislation here, or is that not the problem?

**Dr. MacDonald:** I do not pretend to be an expert on legislation. Any comments I made would be naïve.

I am struck by one interesting point, though. I also have a major interest in research, and I have recently chaired the MRC's standing committee on ethics in human research. Our boards across the country are reviewing research. By definition of the tri-council guidelines for research, we must include people from the community. We cannot review and introduce research programs without community input. It struck me as ironic that we do not have a similar, clear-cut, established role for the community in looking at the education of our physicians and our other health professionals.

It strikes me that one suggestion worthy of discussion is whether, on our major medical school committees, our curriculum committees, et cetera, we should have mandated numbers of people from the community, just as we have mandated numbers of people from the community in research.

**Senator Roche:** We know that one of the stages in the process of death is initial denial, and it appears that the medical profession is almost in denial about the need for palliative care. That was the impression I got from you. Even though a great majority of the students want more education in palliative care, I am wondering, Dr. MacDonald, if you can give us your view. I am sure all the senators on this committee are very much in favour of palliative

L'Ontario a également pris des dispositions plus crédibles pour le financement des médecins de soins palliatifs, car ce n'est pas un domaine qui se prête bien à la facturation des clients. Il n'est pas facile d'appliquer un régime de facturation des clients à l'égard du temps nécessaire pour analyser les problèmes complexes des patients et de leurs familles et pour leur offrir des services de counselling et d'aide psychosociale. Ce n'est pas comme une radiographie pulmonaire. Ces initiatives varient d'un endroit à l'autre.

Néanmoins, je préfère parler plus particulièrement des facultés de médecine et des chefs de nos sociétés nationales. Il est important qu'un groupe communautaire, que notre Sénat, jouent un rôle de chef de file et rencontrent les chefs de nos groupes nationaux, ceux qui sont chargés de tout l'enseignement dans nos facultés de médecine, ainsi que les gens qui dirigent les conseils médicaux du Canada. Vous pourriez rencontrer les représentants du collège royal et du collège des médecins de famille pour voir s'ils conviennent également qu'il existe des écarts dans l'enseignement offert dans nos facultés de médecine, s'ils seraient prêts à adopter certains principes fondamentaux et à faire progresser les choses. C'est dans ces facultés que cela se fait, à l'échelle nationale, et cela ne dépend pas uniquement de la participation des provinces au régime de soins de santé. Les provinces peuvent toutefois être fort utiles en favorisant les conditions dans lesquelles travaillent les médecins qui offrent des soins palliatifs, et peut-être aussi en offrant de l'aide dans le domaine de l'éducation permanente. L'interaction entre les facultés de médecine se fait tout autant à l'échelle provinciale qu'à l'échelle nationale.

**Le sénateur Beaudoin:** Croyez-vous qu'il soit nécessaire de modifier les lois, ou le problème ne vient-il pas de là?

**Dr MacDonald:** Je ne prétends pas être un expert en matière de lois. Mes observations à ce sujet seraient naïves.

Il y a toutefois une chose qui me frappe. Je m'intéresse également beaucoup à la recherche et j'ai récemment présidé le Comité permanent de l'éthique en recherche humaine du CRM. Nos conseils examinent les recherches dans tout le pays. D'après la définition de la recherche que l'on trouve dans les lignes directrices des trois conseils, il faut que des citoyens participent à l'examen et à la mise en place des programmes de recherche. Il me paraît paradoxal qu'il n'existe pas une nécessité semblable et claire de participation des citoyens à l'examen de l'enseignement dispensé à nos médecins et à nos autres professionnels de la santé.

Il faudrait peut-être discuter si, dans nos comités des grandes facultés de médecine, dans nos comités des programmes d'études, et cetera, nous devrions inclure un certain nombre de citoyens mandatés par la collectivité, tout comme on trouve un certain nombre de personnes mandatées par la collectivité dans le secteur de la recherche.

**Le sénateur Roche:** Nous savons que quand quelqu'un meurt, il y a d'abord un déni; il semble que la profession médicale vit un déni à peu près semblable quant à la nécessité des soins palliatifs. C'est l'impression que je retire de vos propos. Il semble également qu'une vaste majorité d'étudiants souhaitent recevoir davantage de cours en soins palliatifs. Je me demande ce que vous en pensez, docteur MacDonald. Je suis sûr que tous les sénateurs



care and, consequently, education in the medical schools that will produce more knowledgeable physicians in this respect. However, what can we do if the medical profession itself does not give a higher priority to the training of physicians in palliative care? We can certainly, I suppose, indicate in our report that this should be done. Is it not a question of reaching into the minds of those who set the curriculum and those who are charged with developing physicians?

We are not charged with developing physicians, but the medical profession is. I am wondering about the effect of our admonition, so to speak. If we put such an admonition in our report, what effect will it have if the medical profession is still wanting to spend their resources and time on curing illness rather than dealing with the facts of death?

**Dr. MacDonald:** Yes. Again, I will try to indicate that I think you have a very strong moral role to play in Canadian society. The teaching of palliative medicine and end-of-life care is not just an educational but also an ethical issue. I think that you may have either the means or the moral authority to move some ideas forward, such as the one in the United States, to see if it is possible to create an authoritative leadership, with some foundation or government support, to draft end-of-life principles and then ask our major medical groups to buy into them. That is what they have done in the United States and it appears to be having a very major impact.

I do not believe that it is satisfactory to leave the process of education, so vital to the community at large, completely without community input. You must think of ways to facilitate real community input.

**Senator Roche:** I take your point that education is too important to be left entirely to the professionals.

Do I take it that you think the report that we are working on might be enhanced if it contained a section on end-of-life principles?

**Dr. MacDonald:** Yes, it would, but I call your attention to your last report. You did recommend that there be increased and better end-of-life training, and that just is not satisfactory. That is not sufficient. This report should be complemented by some proposals on how we can move from rhetoric to tangible improvement. Examples from the United States have demonstrated that they are making major progress by working with the opinion leaders, by working with the people who run the major medical associations, and by working with the people in the medical schools. They are making real strides.

Although I was invited to talk about education, I will point out to you two major changes that have occurred in palliative and end-of-life care in the last five years because they are germane to education, in my opinion. The first is, we are not just talking about cancer. The vast majority of patients in current programs have cancer, but a support study in the United States has clearly shown that the levels of suffering when dying of chronic

de notre comité sont en faveur des soins palliatifs et, par conséquent, d'un enseignement dans les facultés de médecine qui permettra aux médecins d'en savoir davantage dans ce domaine. Mais que pouvons-nous faire si la profession médicale elle-même n'accorde pas une plus grande priorité à la formation des médecins en soins palliatifs? Nous pouvons, je suppose, dire que cela devrait être fait dans notre rapport. Ne s'agit-il pas plutôt d'influencer ceux qui établissent les programmes d'enseignement et qui sont chargés de la formation des médecins?

Ce n'est pas nous qui formons les médecins, c'est la profession médicale. Je me demande si nos admonestations peuvent produire de l'effet. Si nous incluons une telle recommandation dans notre rapport, quel en sera l'effet si la profession médicale préfère encore investir son temps et ses ressources à soigner les maladies plutôt que de s'occuper de la mort?

**Dr. MacDonald:** Pour répondre, je répéterai que vous avez un rôle moral très important à jouer au sein de la société canadienne. L'enseignement de la médecine palliative et des soins en fin de vie, ce n'est pas seulement une question d'éducation, c'est aussi une question d'éthique. Vous avez peut-être à votre disposition les moyens ou l'autorité morale voulus pour faire progresser certaines idées, comme par exemple ce qui se fait aux États-Unis, pour voir s'il est possible de mettre en place un leadership doté d'autorité, avec l'aide d'une fondation ou du gouvernement, pour rédiger des principes relatifs à la fin de la vie et demander ensuite à nos principaux groupes médicaux d'adopter ces principes. C'est ce qui s'est fait aux États-Unis, et cela semble avoir eu un effet important.

Il est insatisfaisant, à mon avis, que la population ne participe pas du tout à l'enseignement, qui est si important pour toute la société. Vous devez trouver des moyens pour faciliter une participation réelle de la population.

**Le sénateur Roche:** Ce que vous dites, c'est que l'enseignement est trop important pour être confié entièrement aux professionnels.

Si je comprends bien, vous croyez que notre rapport serait meilleur s'il contenait une partie sur les principes relatifs à la fin de la vie, n'est-ce pas?

**Dr. MacDonald:** Oui, mais je vous signale que dans votre dernier rapport vous aviez recommandé une augmentation et une amélioration de la formation relative à la fin de la vie, mais ce n'est pas satisfaisant, ni suffisant. Il faudrait que votre rapport contienne également des propositions sur la façon de passer de la théorie à la pratique. Aux États-Unis, il existe des exemples montrant qu'on a réalisé de grands progrès en collaborant avec des leaders d'opinion et avec les dirigeants des principales associations médicales, et en collaborant aussi avec les gens des facultés de médecine. Les Américains font des progrès réels.

Même si vous m'avez invité pour vous parler de l'enseignement, je vais vous signaler deux grands changements qui se sont produits au cours des cinq dernières années dans le domaine des soins palliatifs et des soins en fin de vie, car ces changements sont à mon avis liés à l'enseignement. Le premier, c'est qu'on ne parle pas seulement du cancer. Dans les programmes actuels, une vaste majorité de patients souffrent du cancer, mais aux États-Unis une



obstructive pulmonary disease, AIDS, advanced renal disease, or advanced coronary artery disease, are equivalent to those of cancer patients. The principles should apply broadly through the whole area of chronic illness.

The second important change is that palliative care has currently pretty well been relegated to the very last days of life. This is not sensible or logical, because if you are suffering from, for example, cancer of the pancreas, you did not just develop pain or weight loss in the last month. That pain, weight loss and psychosocial distress, occurred at the time of diagnosis. We are trying to ensure that the principles of palliative care infuse the whole course of a chronic illness and that we get away from this illogical and artificial division, where you are ostensibly being “actively treated” for cancer with chemotherapy that may or may not prolong your life, and then it is time for palliative care. The time for palliative care, logically, is at the onset of the diagnosis of a chronic illness that, predictably, will end your life.

**Senator Roche:** Finally, I am interested in the set of end-of-life principles, which you reviewed rather quickly.

**Dr. MacDonald:** I will leave them with you.

**The Chairman:** I have them, senator.

**Dr. MacDonald:** I would strongly advise obtaining a copy of the document entitled “Approaching Death”, because it is a masterful, thoughtful account of end-of-life care in the United States, much of which is germane to our situation. It has chapters on research and education, and on economic issues in palliative care. It is a very good document. I will either arrange for you to receive a copy or describe how you can do so, and I would be pleased to leave the Milbank report for your perusal.

I would also be pleased to leave you a copy of *Palliative Medicine*. We are rather proud of this book. It is going into its second edition now and we will continue trying to use this as a vehicle to influence teaching in our medical schools.

**The Chairman:** We know that this week, probably tomorrow, in fact, the Senate will receive Bill C-13 — and I am sure Dr. Friesen will prick up his ears from the back of the room — which is concerned with the Canadian Institutes for Health Research. There will be a number of institutes established to conduct research. Do you think it would push the palliative medicine agenda forward if there were to be one on palliative care?

**Dr. MacDonald:** Dr. Friesen and I go back a long way. We were both residents together at the Royal Victoria Hospital and I have discussed this issue with him fairly recently. I feel strongly about one specific idea, and that is that frailty through the course of an advanced, chronic illness is a universal problem. There are steps being taken to improve the lot of frail people, many being psychosocial, and in improved nursing care, home care. I have

étude a clairement démontré que les mourants atteints de maladie respiratoire obstructive chronique, de sida, de maladie rénale ou coronarienne terminale souffrent autant que ceux atteints du cancer. Les mêmes principes devraient s'appliquer à tous les patients qui souffrent de maladie chronique.

Le deuxième grand changement, c'est que les soins palliatifs sont à l'heure actuelle à peu près relégués aux tout derniers jours de la vie. Ce n'est ni sensé ni logique, parce qu'un patient qui souffre d'un cancer du pancréas, par exemple, ne commence pas à souffrir ou à perdre du poids aux derniers mois de sa maladie. La souffrance, la perte de poids et la détresse psychosociale commencent dès le moment où le diagnostic est posé. Nous voulons nous assurer que les principes des soins palliatifs s'appliquent à tout le traitement de la maladie chronique et qu'on mette fin à cette division illogique et artificielle entre le «traitement actif» du cancer, au moyen de la chimiothérapie, qui peut ou non prolonger votre vie, et les soins palliatifs. Logiquement, il faut commencer à offrir des soins palliatifs dès qu'une maladie chronique est diagnostiquée, une maladie dont on peut prédire qu'elle mettra fin aux jours du patient.

**Le sénateur Roche:** Enfin, je m'intéresse aux principes relatifs à la fin de la vie, que vous avez passés rapidement en revue.

**Dr. MacDonald:** Je vous en laisserai copie.

**La présidente:** Nous les avons, sénateur.

**Dr. MacDonald:** Je vous recommande fortement d'obtenir une copie du document intitulé: «Approaching Death», car on y trouve une excellente description des soins en fin de vie aux États-Unis, une description qui s'applique en grande partie au Canada. L'ouvrage comporte des chapitres sur la recherche et l'enseignement, ainsi que sur les questions économiques liées aux soins palliatifs. C'est un excellent document. J'essayerai de vous en transmettre un exemplaire ou de vous indiquer comment vous pouvez vous en procurer un. Si vous le voulez, je vous laisserai avec plaisir le rapport Milbank, afin que vous puissiez le consulter.

Je serais aussi heureux de vous remettre un exemplaire de *Palliative Medicine*. Nous sommes plutôt fiers de notre livre. Il en sera sous peu à sa deuxième édition, et nous continuerons de l'utiliser pour influencer l'enseignement qui se donne dans nos facultés de médecine.

**La présidente:** Cette semaine, en fait probablement demain, le Sénat sera saisi du projet de loi C-13 — je suis certaine que le Dr Friesen, au fond de la pièce, tend l'oreille — qui crée les instituts de recherche en santé. Ces instituts seront établis pour mener des recherches. Croyez-vous qu'on pourrait faire progresser le dossier des soins palliatifs s'il y avait un institut s'intéressant uniquement à ce sujet?

**Dr. MacDonald:** Le Dr Friesen et moi sommes des amis de longue date. Nous avons été résidents ensemble à l'hôpital Royal Victoria, et j'ai discuté de cette question avec lui tout récemment. Je suis fermement convaincu d'une chose, à savoir que la fragilité qui caractérise les patients au stade avancé d'une maladie chronique est un problème universel. On prend des mesures pour tenter d'améliorer le sort de bien des personnes

been discussing with Dr. Friesen the possibility of a biological research initiative to look into the specific causes of muscle weakness and frailty, and whether at this point in our knowledge we might be able to bring forward some interesting research, ideas, and interventions. I think we can.

Dr. Friesen has very helpfully provided me with some suggestions on how this might be achieved through CIHR, and I will try to follow through on those.

The difference is that the United States has published what they call "RFAs". Their National Institutes of Health said, "Here is an area of research where we are not doing very much", and they added financial enticements. I will continue my discussions with Dr. Friesen on whether some type of RFA in an area such as loss of function and frailty would be a reasonable idea in Canada. I think it would.

This discussion does bring up the important issue of getting started. According to the 1996 survey, if you add up the total number of doctors who are supported by their medical school in palliative care in this country, it is under 18. There are biochemistry departments in separate medical schools that have 18 people. We do not have that investment in capacity.

We need to provide grants that would attract some of our best and brightest and enable them to train in some of our first-rate research centres, of which we have very few in Canada. The University of Alberta certainly stands out, as do the Universities of Ottawa, Laval, and McGill, among others. Alternatively, we could send them to train with colleagues in the United States and then attract them back.

We need to build capacity and to establish upfront financial incentives for that. Otherwise, we can always say we should be doing this and that, but there is nobody to do it.

**The Chairman:** Can I just get a clarification on that? Did you say that there are 18 doctors in medical schools across the country with expertise in palliative care?

**Dr. MacDonald:** No, there is a far greater number with expertise. The number I am referring to is from our survey of 1996 when we asked how many people were supported by the medical school in their palliative care activities. That refers to people involved in research and education as well as clinical care. The total added up to just under 18.

There are some medical schools where the investment is very substantial. The University of Alberta is one. The investment at the University of Ottawa is very good, but there were a number of schools in 1996 where respondents to the survey could not identify any individual who was receiving medical school support. There are many doctors in the community. However, I am speaking about capacity, about the people in the medical school who write those textbooks and articles and who do the research and set up the teaching models. That is the group that we are lacking.

fragiles, notamment au chapitre psychosocial et en améliorant les soins infirmiers et les soins à domicile. J'ai discuté avec le Dr Friesen de la possibilité de mener une initiative de recherche en biologie qui s'intéresserait plus précisément aux causes de la faiblesse et de la fragilité musculaire, ainsi qu'à la question de savoir si, à cette étape-ci de nos connaissances, nous pourrions mettre de l'avant des études, des idées et des interventions intéressantes. Je crois que c'est possible.

Le Dr Friesen m'a beaucoup aidé en me suggérant des façons de réaliser cela par l'entremise des instituts de recherche en santé; je tenterai de donner suite à ces suggestions.

La différence, c'est qu'aux États-Unis on a publié ce qu'on appelle des «RFA». Les National Institutes of Health ont jugé que, dans ce domaine, peu de recherche se faisait et ont donc prévu des incitatifs financiers. Je poursuivrai mes discussions avec le Dr Friesen afin de déterminer s'il est raisonnable d'envisager, au Canada, une mesure quelconque pour encourager la recherche sur la perte de fonction et la fragilité. À mon avis, c'est faisable.

Cette discussion soulève l'importante question du lancement d'un projet de recherche. Selon un sondage mené en 1996, le nombre total de médecins appuyés par leur faculté de médecine en soins palliatifs au pays est inférieur à 18. Il y a des départements de biochimie dans diverses facultés de médecine qui comptent 18 personnes. On a donc peu investi dans la capacité.

Il faut prévoir des subventions qui attireraient les plus talentueux et leur permettraient d'étudier dans l'un de nos meilleurs centres de recherche, qui sont peu nombreux au Canada. Il y a d'abord l'Université de l'Alberta, ainsi que les Universités d'Ottawa, Laval et McGill, notamment. On pourrait aussi les envoyer aux États-Unis pour parfaire leur formation, puis leur faire une offre attrayante pour qu'ils reviennent au pays.

Il faut établir une capacité et, pour ce faire, des incitatifs financiers. Sinon, on continuera de dire qu'il faut faire ceci et cela, mais il n'y aura personne pour le faire.

**La présidente:** Pourriez-vous me donner une précision? Avez-vous dit qu'il y a 18 médecins dans les facultés de médecine du pays qui sont experts en soins palliatifs?

**Dr MacDonald:** Non, les experts dans le domaine sont bien plus nombreux. Je vous ai plutôt parlé de notre sondage de 1996 sur le nombre de médecins qui jouissent du soutien d'une faculté de médecine dans leurs activités de médecine palliative. Le nombre de ces médecins, qu'ils fassent de la recherche, de l'enseignement ou de la médecine clinique, est à peine de 18.

Dans certaines facultés de médecine, les investissements sont considérables. C'est notamment le cas de l'Université de l'Alberta. À l'Université d'Ottawa, on a fait de bons investissements, mais plusieurs facultés de médecine, en 1996, n'ont pu indiquer, pendant notre sondage, qui recevait du soutien de leur part. Il y a de nombreux médecins dans la collectivité. Moi, je parle plutôt de la capacité, des gens dans les facultés de médecine qui rédigent les articles et les manuels, qui font de la recherche et qui créent les modèles pédagogiques. Ce sont ces gens-là qui nous manquent.



**The Chairman:** Honourable senators, there are four witnesses joining us for the next panel. Dr. Henry Friesen, Dr. James Young, Professor Brian Mishara, and Mr. Russel Ogden.

**Professor Brian Mishara, Department of Psychology, Université du Québec à Montréal:** I thank honourable senators for the opportunity to appear before this committee to update the report of the Special Senate Committee on Euthanasia and Assisted Suicide, which was released in 1995.

I was impressed by the Senate committee report. It is an elegant document in which the committee's recommendations are clearly presented and well justified by a sophisticated understanding of many of the complex issues involved.

I will make a few brief remarks based upon my experience as the director of the centre for research and intervention on suicide and euthanasia at the Université du Québec à Montréal, and on some of my experiences in investigating human rights issues and euthanasia when I held the Bora Laskin National Fellowship on Human Rights Research, as well as my involvement in several research studies. I will restrict my remarks to results of studies since the report was published in 1995.

Suicide is not illegal in Canada. However, we do not encourage or facilitate suicidal behaviour and section 241 of the Criminal Code makes it illegal to do so. We control access to means of suicide with firearms legislation and barriers on bridges.

When someone is suicidal, or has attempted suicide, we usually do everything possible to avert a lethal outcome. We have suicide prevention programs and we offer the best medical care possible following a suicide attempt. We do so because of the belief, based on years of practical experience and research results, that although people consider suicide because of a situation that they perceive as intolerable and interminable, they are usually mistaken. Despite their belief that their desperation will last for ever, we know that the situation can generally be improved significantly.

Thus, despite the adolescent or middle-aged man's belief that life cannot go on after a girlfriend or spouse terminates a relationship, we know that the anguish need not and will not last for ever.

Similarly, when a clinically depressed person is feeling that life is hopeless, we know that depression may be treated and the feeling of hopelessness can disappear. Experience has shown that suicidal intentions, no matter how rational they may seem to a person, generally reflect reactions to transient, highly emotional situations and that the perception of the hopelessness of the situation usually changes if appropriate help is given.

Many people feel that the desire by people who are terminally or chronically ill to hasten death is different from the suicidal intentions of healthier individuals. Justifications for condoning or facilitating actions to shorten life in these "special populations" by suicide, euthanasia, assisted suicide, or by refusing or discontinu-

**La présidente:** Chers collègues, quatre témoins se joignent maintenant à nous: le Dr Henry Friesen, le Dr James Young, et MM. Brian Mishara et Russel Ogden.

**M. Brian Mishara, professeur, Département de psychologie, Université du Québec à Montréal:** Je vous remercie de m'avoir invité à témoigner devant votre sous-comité de mise à jour du rapport du comité sénatorial spécial sur l'euthanasie et l'aide au suicide, qui est paru en 1995.

J'ai été impressionné par le rapport du comité sénatorial. C'est un document élégant dans lequel les recommandations du comité sont présentées clairement et justifiées par une bonne compréhension des enjeux très complexes en question.

Je ferai de brèves remarques qui se fondent sur mon expérience à titre de directeur du Centre de recherche et d'intervention sur le suicide et l'euthanasie de l'Université du Québec à Montréal ainsi que sur les recherches que j'ai menées sur les questions de droits de la personne relatives à l'euthanasie grâce à une bourse canadienne Bora Laskin pour la recherche sur les droits de la personne, et ma participation à d'autres projets de recherche. Mes remarques se limiteront aux résultats d'études faites depuis la publication du rapport, en 1995.

Le suicide n'est pas illégal au Canada. Toutefois, nous n'encourageons ni ne facilitons le suicide; aux termes de l'article 241 du Code criminel, c'est illégal. Nous contrôlons l'accès aux moyens de se suicider grâce à des lois sur les armes à feu et des garde-fous sur les ponts.

Lorsque quelqu'un est suicidaire ou a tenté de se suicider, nous faisons habituellement l'impossible pour éviter que la mort s'ensuive. Il y a des programmes de prévention du suicide, et nous offrons les meilleurs soins médicaux possible à ceux qui ont tenté de se suicider. Nous le faisons en raison d'une croyance, fondée sur des années d'expérience pratique et de recherche, qui veut que, bien que certains envisagent le suicide dans des situations qu'ils jugent intolérables et interminables, ils ont habituellement tort. En dépit du fait qu'ils croient que leur désespoir perdurera, nous savons que, généralement, la situation peut s'améliorer considérablement.

Ainsi, même si un adolescent ou un homme d'âge moyen croient qu'il ne vaut plus la peine de vivre après que leur amie ou leur femme les a quittés, nous savons que l'angoisse disparaîtra un jour.

De même, lorsqu'une personne souffrant de dépression clinique juge sa vie sans espoir, nous savons que l'on peut traiter la dépression et que le sentiment de désespoir disparaîtra. L'expérience nous a démontré que les intentions suicidaires, même si elles semblent rationnelles à la personne qui les éprouve, reflètent généralement une réaction très émotive, mais transitoire, et que le sentiment de désespoir disparaît habituellement avec toute l'aide nécessaire.

Bien des gens croient que le désir de mourir des patients souffrant d'une maladie chronique ou mortelle diffère des intentions suicidaires des personnes en santé. On estime pouvoir tolérer ou faciliter les mesures visant à abrégier la vie de ces «groupes spéciaux» par le biais du suicide, de l'euthanasie, de



ing treatment are based upon the premise that the suffering or anguish they experience is truly intractable.

If we do condone the hastening of death by these means, we assume that the desire to end life prematurely is determined by the inevitable course of the illness, and that the person's reasons for choosing a premature death are a direct consequence of an irreversible disease process.

It is therefore of crucial importance in any deliberation concerning death and life decisions with persons who are terminally ill, or who suffer chronic degenerative diseases, to consider whether the reasons for hastening death are truly related to irreversible consequences of the illness, or if other factors, such as inadequate pain control or untreated clinical depression, are responsible for the person's desire to end life prematurely.

I have provided members of the committee with an issue of the journal *Omega — Journal of Death and Dying* from 1999, in which I published a synthesis of research and evidence on factors affecting the desire of terminally or chronically ill persons to hasten death. The goal of that article was to understand why some people shorten their lives by suicide, euthanasia, assisted suicide, and refusing and discontinuing treatment, while others choose to continue to live despite a terminal or serious chronic illness. I believe that the results of that analysis may have important policy implications.

Before considering the results of that investigation, I believe it is important to consider several issues that complicate any attempts at legislation in this area.

First, any legislation concerning euthanasia, assisted suicide, or stopping or withholding treatment generally limits access to these means to persons who are considered terminally ill. There have been a number of recent research studies that indicate that for many diseases, cardiovascular disease being an example, it is extremely difficult, if not impossible, to determine whether a person is terminally ill and to make accurate estimates of chances of survival and the timing of death. Although for some diseases, such as certain forms of cancer, survival estimates may be more precise, we are not currently able to accurately determine the probability of survival and reliably categorize people as terminally ill.

Second, one must make an important distinction between decisions concerning life and death that occur in the hours and days before a person would die a natural death, and decisions made earlier. In the Netherlands, euthanasia is practised most frequently when the person is expected to live only several more hours or days.

Furthermore, decisions concerning life and death at this stage are complicated by the fact that the majority of patients who are so close to death have their competence to make meaningful decisions significantly impaired. Lynn and colleagues did a

l'aide au suicide ou de l'interruption ou du refus de traitement en se fondant sur la prémisse selon laquelle rien ne peut faire disparaître leur souffrance ou leur angoisse.

Si nous tolérons l'abrégement de la vie par ces moyens, nous présumons que le désir de mettre fin prématurément à sa vie est déterminé par l'évolution inévitable de la maladie, et que les raisons qui amènent une personne à choisir une mort prématurée sont les conséquences directes du processus irréversible de la maladie.

Il est donc d'une importance primordiale dans toute discussion concernant des décisions de vie ou de mort avec des patients en phase terminale ou souffrant d'une maladie dégénérative chronique de déterminer si les raisons invoquées pour hâter la mort sont véritablement liées aux conséquences irréversibles de la maladie ou si d'autres facteurs, tels qu'un soulagement inadéquat de la douleur ou une dépression clinique non traitée, pourraient expliquer le souhait du patient de mettre fin prématurément à ses jours.

J'ai remis aux membres du comité un exemplaire du périodique *Omega — Journal of Death and Dying* de 1999, où j'ai publié une synthèse de la recherche et des constatations sur les facteurs qui influent sur le souhait qu'ont les personnes souffrant d'une maladie mortelle ou chronique de hâter la mort. Dans cette étude, je voulais comprendre pourquoi certaines personnes écourtent leur vie en se suicidant, avec ou sans aide, en se faisant euthanasier ou en refusant ou en interrompant leur traitement, alors que d'autres choisissent de continuer à vivre en dépit de leur maladie mortelle ou chronique. J'estime que les résultats de cette analyse pourraient avoir d'importantes répercussions sur les politiques.

Avant de se pencher sur les résultats de l'étude, il m'apparaît important d'examiner plusieurs questions qui compliquent toute tentative de légiférer dans ce domaine.

Premièrement, toute loi concernant l'euthanasie, l'aide au suicide et l'interruption de traitement limite généralement l'accès à ces méthodes aux personnes qui sont considérées comme souffrant d'une maladie mortelle. Bien des études menées récemment ont indiqué que, dans le cas de bien des maladies, les maladies cardiovasculaires, notamment, il est extrêmement difficile, sinon impossible, de déterminer si une personne est en phase terminale et d'estimer avec précision les chances de survie et le moment de la mort. Pour certaines maladies, telles que certaines formes de cancer, l'évaluation des chances de survie peut être plus précise, mais nous ne sommes pas encore en mesure de préciser la probabilité de survie et d'établir de façon fiable qu'un patient est en phase terminale.

Deuxièmement, on doit faire une importante distinction entre les décisions concernant la vie et la mort qui sont prises pendant les heures et les jours qui précèdent la mort naturelle, et les décisions prises plus tôt. Aux Pays-Bas, le plus souvent l'euthanasie est pratiquée lorsqu'on estime que la personne n'a plus que quelques heures ou quelques jours à vivre.

De plus, les décisions concernant la vie et la mort prises à cette étape sont compliquées par le fait que la majorité des patients sont si près de la mort qu'ils sont souvent incapables de prendre ces importantes décisions. Lynn et ses collègues ont mené une étude

prospective study that was reported in 1996. They followed patients over a long period of time and determined who actually died. They started with 9,105 terminally ill patients. They learned that of those who had a poor prognosis, that is, a 20 to 29 per cent chance of surviving for six months, over half were so impaired that they had problems responding to any verbal stimulus or with moving their eyes or bodies purposefully, and 59 per cent were too sick to engage in meaningful conversation.

Therefore, meaningful, informed consent is often impossible at this stage in the development of a life-threatening illness. The frequent occurrence of cognitive impairment near the end of life may seem less important if advance directives are available that indicate the individual's previous desires. However, some recent research suggests that what people think they will want at a future time, or when their situation changes in a certain way, is not consistently related to what they eventually do want when they are in that situation.

For example, I am just completing a longitudinal investigation where we followed 101 persons with advanced AIDS. We evaluated plans and intentions to foreshorten life by suicide, euthanasia, and assisted suicide. We followed people, and several have died.

We find very little consistency in follow-up data at six-month intervals concerning the extent of the intention of these people to end their lives prematurely. As one example, an individual clearly complained that he had no desire to continue living if he were ever bedridden or a burden to others. He said that he had the means available to take his life, and a willing assistant. When this person found himself in a situation much worse than he ever imagined — he was bedridden, blind, and dependent upon medical apparatus to survive — he did everything possible to live another few minutes, hours, or days despite constant suggestions by his companion that perhaps the time to die by assisted suicide had arrived.

In another instance, a person who vehemently expressed the view that only God can end life and one must go on regardless, was pleading for someone to end his life immediately during the last two days of agony before his death.

Most people in Canada believe that individuals with chronic degenerative diseases such as senile dementia, multiple sclerosis, and many forms of severe handicaps, would have a strong desire to hasten death. However, research studies clearly indicate that these diseases, as well as several other disabilities, are not linked to an increased desire for suicide, euthanasia, and assisted suicide. Research shows that the extent to which people with chronic diseases desire to end their lives prematurely varies according to the disease and the stage and progress of the illness. For example, persons with AIDS have the highest risk of ending their lives by suicide in the months after they first learn that they are HIV positive, even before they have experienced any symptoms.

prospective qui a fait l'objet d'un rapport en 1996. Ils ont suivi des patients sur une longue période de temps et ensuite déterminé qui était mort. Ils ont commencé avec 9 105 patients en phase terminale. Ils ont constaté que, parmi tous ceux qui avaient un mauvais pronostic, soit de 20 à 29 p. 100 de chances de survivre six mois, plus de la moitié avaient du mal à réagir aux stimuli verbaux ou à bouger leur corps ou leurs yeux délibérément, et que 59 p. 100 étaient trop malades pour participer à une conversation intelligente.

Par conséquent, le consentement éclairé est souvent impossible à cette étape de l'évolution d'une maladie mortelle. La fréquence des déficiences intellectuelles à la fin de la vie peut sembler moins importante si le patient a donné des directives préalables qui indiquent quels étaient ses souhaits antérieurs. Toutefois, des études récentes nous mènent à croire que ce que les gens croient qu'ils voudront dans l'avenir ou lorsque leur situation changera ne correspond pas nécessairement à ce qu'ils feront lorsqu'ils seront dans cette situation.

Par exemple, je viens de terminer une étude longitudinale auprès de 101 personnes souffrant de sida évolué. Nous avons évalué les projets et les intentions d'abrégé la vie par le biais du suicide, de l'euthanasie et de l'aide au suicide. Nous avons suivi ces 101 personnes, et plusieurs sont décédées.

Nous avons constaté que les données sur les intentions de ces patients de mettre fin à leur vie prématurément correspondaient peu aux données recueillies six mois plus tard. Ainsi, un de ces patients avait clairement indiqué qu'il ne souhaiterait pas continuer à vivre s'il était confiné à son lit ou un fardeau pour les autres. Il avait déclaré avoir les moyens de mettre fin à ses jours et connaître quelqu'un qui était disposé à l'aider. Lorsqu'il s'est trouvé dans une situation bien pire que ce qu'il avait pu imaginer — il était confiné à son lit, aveugle et dépendant de dispositifs médicaux pour sa survie — il a fait l'impossible pour vivre encore quelques minutes, quelques heures, quelques jours, en dépit du fait que son compagnon lui ait plusieurs fois laissé entendre que le temps était peut-être venu pour qu'on l'aide à se suicider.

Une autre personne qui avait déclaré avec véhémence que seul Dieu peut mettre fin à la vie et qu'on doit continuer à vivre coûte que coûte a demandé qu'on mette fin à ses jours sans plus tarder deux jours avant de mourir.

Nombreux sont les Canadiens qui croient que les personnes souffrant de maladies dégénératives chroniques, telles que la démence sénile, la sclérose en plaques et bien des handicaps graves, souhaiteraient ardemment hâter leur mort. Toutefois, les études montrent clairement que ces maladies, ainsi que plusieurs autres handicaps, ne sont pas liées à un désir accru de se suicider, avec ou sans aide, ou de se faire euthanasier. La recherche indique que le souhait de mourir prématurément chez les personnes souffrant d'une maladie chronique varie selon la maladie et l'étape où en est la maladie dans son évolution. Ainsi, les sidéens sont plus susceptibles de se suicider dans les mois suivant le diagnostic de séropositivité, avant même que n'apparaissent les premiers symptômes.



Furthermore, the principal reasons people with terminal illness choose to end their lives prematurely depend upon the nature of the terminal disease. In cancer patients, uncontrolled pain and suffering has been found to be an important factor influencing decisions to hasten death. The research findings clearly suggest that, as the Senate committee previously recommended, there is a need to develop better policies and practices in order to ensure that all patients have access to adequate pain control and reduction of suffering. Although this is true for cancer patients, research data has not found significant links between pain and suffering and the desire for euthanasia or assisted suicide in other illnesses.

With cancer patients, despite the increased availability of palliative care services for the terminally ill, as Dr. MacDonald mentioned, in Canada people must have the label of "terminal" and usually have stopped active treatment of the illness in order to have access to palliative care. In Canada, palliative care is reserved for a certain elite, usually those who suffer from cancer, who have stopped all other treatment, and who are fairly advanced in the illness. There is no indication that they are any more in need of good palliative care than persons suffering from other diseases and at other stages in the development of the illness.

Besides studies relating pain in cancer patients to the desire to hasten death, there has been considerable research in all diseases on the link between depression and the desire to end life prematurely. The majority of people who stop treatment, refuse treatment, or choose assisted suicide or euthanasia, can be diagnosed as suffering from clinical depression.

In some instances, the person was clinically depressed before he or she became ill and the illness is an additional reason to express a pre-existing desire to die. However, it is more often the case that the depression is related to the effects of the illness or its treatment. It is related to loss of abilities, social isolation, feeling useless, being a burden, and side-effects of treatment such as certain medications. It is possible that treatment of the depression will reduce or eliminate the desire to hasten death.

As I mentioned, in some instances, the depression is what is called "iatrogenic", that is, it is a side-effect of the medications used to treat the illness. In other circumstances, for example with degenerative brain diseases, the depression may be a direct physiological consequence of the terminal illness.

In any consideration of legislation to allow or facilitate means of hastening death, including refusing and stopping treatment, I believe that members of this Senate committee should consider that before allowing access to any form of a premature death, we have an obligation to determine whether the patient suffers from clinical depression and, if so, provide adequate treatment.

The basic premises underlining most arguments in favour of some form of access to a premature death are based upon the belief that, under some circumstances, a person may be better off dead. Furthermore, it is assumed that a person is capable of

De plus, les raisons pour lesquelles les patients en phase terminale choisissent de mettre fin à leurs jours prématurément dépendent de la nature de la maladie. Chez les cancéreux, la souffrance et la douleur qu'on ne soulage pas est un facteur qui influe grandement sur la décision de hâter la mort. Les résultats des recherches indiquent clairement que, comme le comité sénatorial l'a recommandé, il faut élaborer de meilleures politiques et pratiques afin de s'assurer que l'on soulage la douleur et que l'on réduise la souffrance des patients. C'est vrai pour les cancéreux, mais les données ne nous ont pas permis d'établir de liens significatifs entre la douleur et la souffrance et le souhait de se faire euthanasier ou d'avoir de l'aide pour se suicider chez les patients atteints d'autres maladies.

Chez les cancéreux, en dépit du fait que les soins palliatifs pour les patients en phase terminale sont plus disponibles qu'auparavant, comme l'a mentionné le Dr. MacDonald, au Canada on doit être considéré comme étant en phase terminale et avoir interrompu le traitement actif de la maladie afin d'obtenir des soins palliatifs. Au Canada, les soins palliatifs sont réservés à une certaine élite, habituellement ceux qui souffrent du cancer, qui ont mis fin à tout traitement et dont la maladie est très évoluée. Pourtant, rien n'indique qu'ils aient davantage besoin de bons soins palliatifs que les personnes atteintes d'une autre maladie ou à une autre étape de l'évolution de la maladie.

Outre les études sur les liens entre la douleur chez les cancéreux et le souhait de hâter la mort, des recherches considérables ont été menées sur le lien entre la dépression et le souhait de mettre fin à ses jours prématurément, quelle que soit la maladie. La majorité des patients ayant interrompu le traitement, refusé le traitement ou choisi l'aide au suicide ou l'euthanasie peuvent faire l'objet d'un diagnostic de dépression clinique.

Dans certains cas, le patient souffrait de dépression clinique avant de devenir malade, et la maladie n'a fait qu'ajouter un motif à ceux qui le poussaient à souhaiter la mort. Toutefois, le plus souvent, la dépression est un des effets de la maladie ou du traitement. Elle est liée à la perte de capacité, à l'isolement social, à l'impression d'être inutile et un fardeau et aux effets secondaires de certains médicaments. Il est possible que le traitement de la dépression réduise ou élimine le souhait de mourir de façon hâtive.

Comme je l'ai mentionné, dans certains cas la dépression est ce qu'on appelle «iatrogène», c'est-à-dire qu'elle résulte des médicaments servant à soigner la maladie. Dans d'autres cas, comme pour les maladies dégénératives du cerveau, la dépression peut être une conséquence physiologique directe de la maladie.

Dans leur examen d'une loi permettant ou facilitant la mort hâtive, y compris le refus et l'interruption de traitement, j'estime que les membres du comité devraient envisager l'obligation de déterminer si le patient souffre de dépression clinique et, dans l'affirmative, de dispenser le traitement requis avant que l'on donne à un patient les moyens de hâter sa mort.

La plupart des arguments pour l'accès à une mort prématurée se fondent sur la croyance selon laquelle, dans certaines circonstances, il est préférable de mourir. De plus, on tient pour acquis que le patient est en mesure de comprendre que ces circonstances



realizing that the circumstance exists or is imminent, or someone else, for example, a physician or family member, is capable of making such a determination.

Survey studies suggest that most Canadians believe that there exist circumstances where death is preferable to continuing to live. However, research has consistently shown that our beliefs about what we think is intolerable for others or ourselves is often inaccurate. We are not very good at predicting what we will want in future circumstances, and we are even less accurate at predicting what someone else will desire.

Finally, I would like to discuss the role of caregivers, including physicians and family members, in end-of-life decision-making. Research indicates that family members often knowingly do not respect the patient's expressed desires. Some studies show that family members tend to rely solely upon recommendations of physicians in these matters. Surveys also indicate that physicians and other caregivers tend to feel ill at ease and lack clear guidance concerning how to react to family members and advise them. There is a clear need for development of guidelines and training for physicians and other caregivers in this matter.

My review of recent research indicates that we need to conduct more investigations to better understand why some individuals choose to end their lives prematurely and others continue to live despite terminal illness or a serious degenerative disease. There is a particular need for evaluative research to determine the effectiveness of interventions and programs that may reduce the desire for a premature death in the terminally ill by suicide, euthanasia, or assisted suicide, as well as decisions to stop or refuse treatment.

Although depression is clearly linked to a desire to hasten death, we do not yet have clear indications that the relief of depression diminishes this desire. We need to test different pilot programs that focus on improving the quality of life, and controlling and reducing clinical depression, in order to determine which interventions may be effective.

**The Chairman:** Senators, the next witness is Dr. James Young.

**Dr. James G. Young, Chief Coroner, Office of the Chief Coroner of Ontario:** It is an honour and a pleasure to be invited back to the Senate hearings. It is not often that anyone wants to see or hear from a coroner a second time. I thank you for that privilege.

When I appeared the last time, it was in an educational role, to explain the practical aspects of investigating deaths and how euthanasia played out in everyday life in Ontario. The Office of the Chief Coroner took no position in regards to broadening or not broadening the definition of euthanasia.

However, we do strongly support the work of this Senate committee, including the earlier report. I would be remiss if I did not commend you for it. It was an excellent piece of work.

existent ou sont imminentes ou que quelqu'un d'autre, par exemple le médecin ou un membre de la famille, est en mesure de prendre cette décision.

Plusieurs études laissent croire que la plupart des Canadiens estiment qu'il y a des circonstances où la mort est préférable à la vie. Toutefois, il a été démontré à maintes reprises que nous avons souvent tort de juger certaines choses intolérables pour d'autres ou pour nous. Nous ne savons prévoir avec précision ce que nous voudrions dans l'avenir, et nos prévisions de ce que les autres voudront sont encore moins précises.

Enfin, j'aimerais aborder le rôle des soignants, y compris les médecins et les membres de la famille, dans le processus décisionnel de fin de vie. Les recherches indiquent que les membres de la famille vont souvent délibérément à l'encontre des souhaits exprimés par le patient. Des études indiquent que les membres de la famille ont tendance à s'en remettre uniquement aux recommandations des médecins. Les études indiquent aussi que les médecins et les autres dispensateurs de soins se sentent mal à l'aise et ne savent trop comment réagir ni comment conseiller les membres de la famille. Manifestement, il faut élaborer des lignes directrices et prévoir de la formation pour les médecins et les dispensateurs de soins de santé à ce chapitre.

D'après l'examen que j'ai fait des recherches récentes, il faut faire davantage d'enquêtes pour mieux comprendre pourquoi certaines personnes choisissent de mettre fin prématurément à leur vie et pourquoi d'autres continuent de vivre malgré des maladies mortelles ou dégénératives graves. Il faut particulièrement faire des recherches évaluatives pour déterminer l'efficacité des interventions et des programmes qui pourraient réduire le désir, chez les personnes souffrant de maladies mortelles, de mettre fin prématurément à leur vie, que ce soit par le suicide, l'euthanasie, l'aide au suicide, ou encore la décision d'interrompre ou de refuser les traitements.

Même s'il existe un lien clair entre la dépression et le souhait de hâter la mort, nous ne savons pas encore clairement si le soulagement de la dépression réduit ce souhait. Il faut mettre en oeuvre divers programmes pilotes qui mettent l'accent sur l'amélioration de la qualité de vie, ainsi que sur le contrôle et la réduction de la dépression clinique, afin de déterminer quelles sont les interventions les plus efficaces.

**La présidente:** Sénateurs, notre témoin suivant est le Dr James Young.

**Dr James G. Young, coroner en chef, Bureau du coroner en chef de l'Ontario:** C'est un plaisir et un honneur d'être invité de nouveau aux audiences du Sénat. Il est plutôt rare que quelqu'un veuille entendre ou voir deux fois un coroner. Je vous remercie de ce privilège.

La dernière fois que j'ai comparu, mon rôle était d'expliquer les aspects pratiques des enquêtes sur les décès et comment l'euthanasie est une réalité de tous les jours en Ontario. Le Bureau du coroner en chef n'avait exprimé aucune opinion quant à l'étendue que devrait avoir la définition de l'euthanasie.

Toutefois, nous appuyons sans réserve le travail de votre comité, y compris le rapport antérieur. Je me dois de vous en féliciter. C'était un excellent rapport.

To recap very briefly, the Ontario coroners, who investigate 30,000 deaths a year, are all medical doctors. They investigate deaths in homes, in institutions, in all settings in the province.

Deaths where we are dealing with palliative care and with potential euthanasia fall into the two broad categories of home deaths and deaths in institutions. I will briefly recap our concern in each area.

There is no question in our minds that there are probably instances of euthanasia that occur in home settings. How many, and where and when, we frankly do not know, for a number of reasons. Very often, the coroner is not called to a home scene to begin with because the death is expected. There are no charts available; the patient usually has access to opiates and strong analgesics. If no one at the scene indicates that anything is amiss, then it is not obvious to us that there is the need for an investigation or that anything has happened.

There are occasions when coroners are called on weekends, on nights, when other doctors do not want to get out of bed, but coroners are forced to, and they do attend. We have made it clear to coroners that if they attend a scene where there seems to be an unusually large number of people, some of whom seem to be there in an advocacy role, that they should pay close attention to those investigations and, in most instances, order autopsies.

As I indicated last time, even autopsies are difficult because the patient is already on strong analgesics, and interpreting the dose level relative to the death is very problematic. However, there are instances potentially where drugs that were not prescribed may be found in the system.

Of greater concern to our office, and of continuing concern, is monitoring very closely what goes on in institutions. The risk of someone deciding that euthanasia is in order and not properly discussing it with or informing patients or families and, in fact, running amok at an institution is of concern to us. Coroners and medical examiners in North America are, unfortunately, called to investigate such cases from time to time. Again, these investigations are very complex, very difficult, but they are performed and, on occasion, do result in instances of this type being uncovered.

Our preference in Ontario has never been to debate this issue in the courts, but it has been necessary for us to have an inquest into the issue of euthanasia and three criminal trials that involved a family, a nurse, and a doctor, where we believed that life had been ended or attempted to be ended prematurely.

One reason for pursuing these cases in the courts was because we believed that these people should not be making decisions

Je vais récapituler très brièvement. Les coroners de l'Ontario, tous médecins, font enquête chaque année sur 30 000 décès. Ces décès peuvent survenir à la maison, en établissement, dans tous les contextes de la province.

Les enquêtes que nous faisons en matière de soins palliatifs et d'euthanasie possible se divisent en deux grandes catégories, celle des décès à la maison et celle des décès en établissement. Je vais brièvement passer en revue ce qui nous préoccupe dans chacune de ces catégories.

Il ne fait aucun doute pour nous qu'il y a probablement des cas d'euthanasie parmi les décès à la maison. À vrai dire, nous ne savons ni le nombre, ni le lieu ni le moment, et ce, pour un certain nombre de raisons. Très souvent, le coroner n'est pas appelé à se rendre sur les lieux, parce que le décès du patient est prévu. Il n'existe pas de tableaux à ce sujet; généralement, le patient a à sa disposition des opiacés et de puissants analgésiques. Si personne sur les lieux ne signale d'anomalies, nous ne pouvons pas toujours savoir qu'il faut tenir une enquête ou que quelque chose s'est produit.

Il arrive parfois que les coroners sont appelés à travailler les fins de semaine, ou la nuit, quand les autres médecins ne veulent pas sortir de leur lit; les coroners, eux, sont obligés de répondre à l'appel, et ils le font. Nous avons clairement expliqué aux coroners qu'ils doivent apporter une attention particulière aux cas où il y a sur les lieux du décès un nombre inhabituel de personnes, dont certaines semblent être là pour faire du prosélytisme. Dans ces cas, ils devraient apporter une attention particulière à ces enquêtes et, dans certains cas, exiger des autopsies.

Comme je l'ai dit la dernière fois, même les autopsies ne donnent pas toujours des résultats clairs, car le patient a déjà consommé des analgésiques puissants, et il peut être très difficile d'interpréter le rapport entre les doses consommées et le décès. Il existe toutefois des cas où l'on peut trouver dans le système du patient des médicaments qui ne lui avaient pas été prescrits.

Ce qui inquiète plus particulièrement notre bureau, c'est qu'il faut surveiller de près ce qui se fait dans les établissements. Nous craignons la possibilité que quelqu'un ne décide qu'une euthanasie est à propos, sans en avoir discuté avec le patient ou la famille, et que l'établissement, enfin, perde le contrôle de la situation. Les coroners et les médecins légistes d'Amérique du Nord sont malheureusement appelés à faire occasionnellement des enquêtes sur de tels cas. Ce sont des enquêtes très complexes, très difficiles, mais il y en a, et elles révèlent à l'occasion des problèmes de ce genre.

En Ontario, nous préférons ne pas débattre de ces questions devant les tribunaux, mais nous avons dû faire une enquête sur des cas d'euthanasie, et trois procès au criminel ont eu lieu dans des cas mettant en cause un membre de la famille, une infirmière et un médecin. Dans ces cas, nous pensions qu'on avait mis fin prématurément aux jours du patient ou qu'on avait essayé de le faire.

Si nous avons entamé ces poursuites devant les tribunaux, c'est entre autres parce que nous pensions que ces gens ne devraient



unilaterally, and that they should not be martyred for their actions but, rather, should stand trial for them.

The common feature in all of these cases was that it was very difficult to decide what to charge people with and how to proceed with the prosecution.

That led to our recommendation, which was adopted by your committee and which we still feel is very important, that the definition of euthanasia should be clear in the law and that there should be a clear section in the Criminal Code that states: "This is where you go beyond euthanasia and this is what the appropriate punishments are for that". That draws the line, wherever it may be, and firmly. It continues to be a concern to us that it is not as clear as it should be.

In inquests at the Christopher Robin Home, the issue was that the children who were receiving active care were suddenly classified as palliative without consultation with the family or adequate testing, and without adequate charting. In many instances, opiates were added to their medical regime for no obvious reason. It became a question of institutional blindness where people, we believe in good faith, felt that they were offering what they described as comfort care, but in isolation, without discussion, and without considering alternatives. The holding of the inquest became an important educational tool.

Currently, there now appears to be a little less debate concerning euthanasia. Our belief is that this is just a low point in the cycle, and that something will cause the debate to reappear at some point.

We have been involved in some investigations of euthanasia-related cases but we have had no further prosecutions in the past five years in Ontario.

We have conducted extensive education in regards to palliative care. I want to be very clear that I, along with my colleagues across the country, strongly support the concept of and the need for palliative care.

Regarding the principles that Dr. MacDonald talked about earlier, I remind the committee that when there was a raging debate about "do not resuscitate" orders, people got together and established principles that became the norm. Consequently, there is little debate any more on that topic. There is great value in establishing principles and in giving people a comfort level about palliative care.

We find, as we continue to lecture, that there is a broad misunderstanding in the medical community about palliative care. We are not looking for palliative care to be discontinued, but rather for it to be carried out in an appropriate manner. We are clear about our guidelines and we expect palliative care to take place. We expect reasonable doses of drugs to be given and we understand that those drugs may shorten someone's life and that that is appropriate. What we cannot tolerate is someone purposefully ending a life by giving either an inappropriate drug

pas prendre de décisions unilatérales de ce genre, qu'ils ne devraient pas être les martyrs d'une cause, mais plutôt répondre de leurs actes devant les tribunaux.

Dans toutes ces affaires, le point commun, c'est qu'il était très difficile de décider quelles accusations porter et comment le procès devait se dérouler.

C'est pourquoi nous avons formulé une recommandation, qui a été adoptée par votre comité et que nous estimons encore très importante, pour que la définition de l'euthanasie soit claire dans les lois et pour qu'un article indique clairement dans le Code criminel quelles sont les limites de l'euthanasie et les sanctions applicables à ceux qui franchissent ces limites. De cette façon, les limites sont claires et fermes. Nous continuons de nous inquiéter de ce que ces limites ne sont pas aussi claires qu'elles le devraient.

Dans les enquêtes sur le foyer Christopher Robin, le problème, c'est que des enfants qui recevaient des soins actifs étaient tout à coup classés comme patients de soins palliatifs, sans que la famille ait été consultée, sans que les tests nécessaires aient été réalisés et sans les mentions qui s'imposent au dossier. Dans bon nombre de cas, on avait ajouté des opiacés aux médicaments administrés à ces patients sans raison évidente. Dans ces cas, nous avons estimé que les soignants étaient de bonne foi lorsqu'ils croyaient offrir des soins visant à réconforter le patient, mais de façon isolée, sans discussion, et sans tenir compte des solutions de rechange. Les enquêtes ont permis de faire un travail important d'éducation.

À l'heure actuelle, il semble que le débat sur l'euthanasie a perdu un peu d'ampleur. D'après nous, il s'agit d'un ralentissement dans le cycle, et les événements susciteront de nouveau ce débat.

Certains cas d'euthanasie ont fait l'objet d'enquête, mais il n'y a pas eu d'autres poursuites en Ontario au cours des cinq dernières années.

Nous avons mis en oeuvre de grandes initiatives d'éducation au sujet des soins palliatifs. Je tiens à dire clairement que, comme tous mes collègues au Canada, je suis très en faveur du concept des soins palliatifs et que je reconnais le besoin d'offrir ces soins.

Au sujet des principes dont le Dr MacDonald a parlé tout à l'heure, je rappelle au comité que quand il y a eu un tollé de protestations au sujet des ordonnances de non-réanimation, les gens ont collaboré et élaboré les principes qui sont devenus la norme. Par conséquent, ce n'est plus un sujet très discuté. Il est très important d'élaborer des principes en matière de soins palliatifs et de rassurer la population à ce sujet.

Dans les cours théoriques que nous donnons, nous constatons qu'il existe un grand malentendu au sujet des soins palliatifs dans le monde médical. Nous ne voulons pas que ces soins palliatifs cessent d'être offerts, mais plutôt qu'ils soient offerts de la bonne façon. Nos lignes directrices sont claires, et nous voulons que les soins palliatifs soient offerts. Nous voulons que des doses raisonnables de médicaments soient administrées et nous comprenons que ces médicaments peuvent abrégé la vie d'un patient et que c'est acceptable. Ce que nous ne saurions tolérer, c'est que



or an inappropriate dose of a drug. We want to make these issues clearer.

Since we were last here five years ago, unfortunately Dr. Kevorkian was able to continue his activities for some period of time in the United States. When one Ontario citizen crossed the border for a consultation and returned, we launched a dual investigation with Michigan into Dr. Kevorkian's activities. From a personal point of view, I am pleased to say that Dr. Kevorkian is languishing at the state's pleasure right now and is not practising his brand of judge and jury.

Over the past few years, he appeared to become bolder. He widened his methods and became even less choosy about the situations in which he agreed to intervene. Therein lies the risk or danger when one person starts out on a personal crusade.

Much of our information is anecdotal, but we believe there have been some improvements in pain care. I fully support Dr. MacDonald's comment that there is a long way to go. We hear about it when we go to investigate deaths and the families make complaints. We strongly believe that we have a long way to go in education on palliative care. I was very interested in, and would agree entirely with, Dr. MacDonald's comments.

We conclude that much more needs to be done in the area of pain control. If adequate pain control is available, many people will choose that alternative rather than considering or debating euthanasia.

We believe the Criminal Code, as I said earlier, should be clarified and a separate offence created. I know it is not on the table right now, but if ultimately there was a change, we continue to believe there would be a role for coroners and medical examiners in monitoring euthanasia.

There still remains a great deal to be done in clarifying the issues in the debate. It is very easy to produce a survey favourable to change if you ask certain questions. Asking a cancer patient in tremendous pain about euthanasia, without describing alternatives, will certainly get a favourable answer. Asking the same question of a patient on the first day of a diagnosis of AIDS may bring a very different answer. I find little solace in surveys because they are fatally flawed from the beginning, in my opinion.

**Dr. Henry Friesen, President, Medical Research Council of Canada:** Madam Chair, I have read very carefully the presentations of a number of witnesses, as well as the background information, and I will first offer some context for my remarks about research.

I begin by quoting from an American playwright: "To intervene in the lives of our fellow human beings, in their pain and their suffering, is the most authentic answer to the question of our humanity."

I see your focus on this important issue, in leading this inquiry, as an expression of your humanity.

quelqu'un abrège à dessein la vie d'un patient en lui administrant soit un médicament inapproprié, soit une dose excessive d'un médicament. Nous voulons que ces questions soient précisées.

Depuis que nous avons comparu il y a cinq ans, le Dr Kevorkian a malheureusement pu poursuivre ses activités aux États-Unis. Lorsqu'un citoyen de l'Ontario a traversé la frontière pour le consulter, nous avons lancé après son retour une double enquête, avec l'État du Michigan, sur les activités du Dr Kevorkian. Personnellement, je suis heureux de vous signaler que le Dr Kevorkian languit actuellement derrière les barreaux et ne peut plus rendre ses arrêts de mort.

Il était devenu plus téméraire au cours des dernières années. Il avait élargi ses méthodes et était devenu moins sélectif quant aux cas dans lesquels il accepte d'intervenir. C'est cela qui est dangereux dans les croisades personnelles.

En fait de renseignements, nous avons surtout des anecdotes, mais nous croyons qu'il y a eu des améliorations dans le traitement de la douleur. Je suis entièrement d'accord avec le Dr MacDonald lorsqu'il dit qu'il reste encore beaucoup à faire. C'est ce que nous disent les familles quand nous faisons des enquêtes sur les décès. Nous sommes persuadés qu'il reste encore beaucoup à faire dans l'enseignement des soins palliatifs. J'ai trouvé les observations du Dr MacDonald très intéressantes, et je suis entièrement d'accord avec ce qu'il a dit.

Pour conclure, il reste beaucoup à faire encore dans le contrôle de la douleur. Si on leur offre des moyens suffisants de contrôler la douleur, bon nombre de gens préféreront utiliser ces moyens plutôt que d'envisager l'euthanasie ou d'en discuter.

Comme je l'ai déjà dit, nous pensons que le Code criminel devrait être plus précis et qu'il faudrait créer un délit distinct. Je sais que cela ne fait pas partie du sujet que vous examinez, mais si vous apportiez des changements, nous croyons encore que les coroners et les médecins légistes auraient un rôle à jouer dans la surveillance des cas d'euthanasie.

Il reste encore beaucoup à faire également pour ce qui est de préciser les enjeux du débat. En posant certaines questions, il est très facile de produire un sondage montrant une opinion favorable au changement. Demandez à un patient atteint d'un cancer qui souffre terriblement s'il est en faveur de l'euthanasie, sans lui décrire les solutions de rechange, et il vous répondra certainement par l'affirmative. Posez la même question à un patient qui vient d'apprendre qu'il est atteint du sida, et la réponse sera peut-être bien différente. Je n'accorde pas beaucoup de foi aux sondages, car ils sont généralement biaisés au départ, à mon avis.

**Dr Henry Friesen, président, Conseil de recherches médicales du Canada:** Madame la présidente, j'ai lu attentivement les témoignages d'un certain nombre de témoins, ainsi que les renseignements de base, et je vais commencer par situer mes remarques au sujet de la recherche dans leur contexte.

Mon mémoire commence par une citation d'un dramaturge américain: «La façon la plus authentique de vérifier notre humanité, c'est d'aider les autres humains et d'alléger leurs souffrances».

En mettant l'accent sur cette question importante, en dirigeant cette enquête, vous exprimez votre humanité.

End-of-life care is not only about pain and cancer. I echo the remarks of Dr. MacDonald. There is a contextual expression of end-of-life care. There are different trajectories of end of life, depending on the nature of the underlying illness. There is a different contextual arrangement that is applicable, depending on the age. It is a very different situation when a child is dying, compared to someone who has chronic illness, particularly in the form of loss of neurological function over many years. There is a difference in the family support systems that encourage and support individuals who are dying. There is also an acknowledgement, as I read the views of a number of experts, that we simply lack a lot of baseline information, so that when we try and evaluate whether progress is being made, too much still depends on anecdote.

Finally, as part of the contextual statements, I also recognize that end-of-life care is part of Canada's health care system, with its varied expressions in the different provinces. A provincial role and responsibility is paramount in considering this issue.

I will address particularly the role of the agency that I have the honour to head, the Medical Research Council of Canada, as the lead federal agency supporting research coast to coast, across the full spectrum, including end-of-life care research issues.

I am also here to tell you what Senator Carstairs has already indicated: The MRC's proud record of achievement and its legacy of 40 years' contribution to developing the research capacity in this country will end when Bill C-13 is enacted, and will have its new expression in the Canadian Institutes for Health Research.

The question is often asked, how much does the Medical Research Council invest in end-of-life care research issues? The question is straightforward, but I must tell you the answer is not. Science is an endless frontier and end-of-life issues have many antecedents. Arguably, research into those antecedents is part of end-of-life research.

Let me give you an example. Dr. Tony Yaksh is one of the premier authorities in the world on pain management. His insight was developed in pursuit of an inquiry into pain mechanisms in the spinal cord. There are today, literally millions of people around the world who benefit from the application of his insight into pain management at various stages. Research can focus on the care of people with terminal illnesses, but, happily, terminal illnesses of yesterday are now treatable and sometimes preventable illnesses today.

I graduated when there was a raging polio epidemic in Winnipeg. Today, indeed for the last decade, there is no more polio in the North American hemisphere. When I graduated, the management of the terminal illness of individuals with polio was a huge challenge. How do we cope with individuals in iron lungs on a protracted, chronic basis?

Les soins en fin de vie ne s'appliquent pas seulement à la douleur et au cancer. Je suis d'accord avec les observations du Dr MacDonald. Les soins en fin de vie s'inscrivent dans un contexte. La fin de la vie diffère de la nature de la maladie. L'âge influe également sur ce contexte. La situation est bien différente si c'est un enfant qui meurt, plutôt que quelqu'un qui souffre d'une maladie chronique, surtout s'il s'agit d'une perte de fonctions neurologiques étendue sur plusieurs années. Les systèmes de soutien familial qui encouragent et appuient les mourants sont également différents. D'après ce que disent un certain nombre d'experts, on reconnaît également que nous manquons d'informations de base et que nous devons encore trop nous fier aux anecdotes lorsqu'il s'agit d'évaluer les progrès réalisés.

Enfin, nous reconnaissons aussi que les soins en fin de vie font partie du régime de soins de santé du Canada et que leurs prestations varient selon les provinces. Il est essentiel que les provinces aient des fonctions dans ce domaine.

Je vais vous parler plus particulièrement du rôle de l'organisme que j'ai l'honneur de diriger, le Conseil de recherches médicales, qui est la principale agence fédérale chargée d'appuyer la recherche d'un océan à l'autre, dans tous les domaines, y compris la recherche sur les soins en fin de vie.

Je suis également venu vous dire ce que le sénateur Carstairs a déjà mentionné, c'est-à-dire que le CRM, avec ses grandes réalisations et ses 40 ans de contribution à l'élaboration de ressources de recherche au Canada, cessera d'exister lorsque le projet de loi C-13 sera adopté. Il se réincarnera dans les Instituts de recherche en santé du Canada.

On demande souvent combien le Conseil de recherches médicales investit dans la recherche sur les soins en fin de vie. La question est claire, mais je dois avouer que la réponse ne l'est pas. La science est sans limite, et les questions liées à la fin de la vie comportent de nombreux facteurs. On pourrait dire que la recherche sur ces facteurs fait partie de la recherche sur les soins en fin de vie.

Permettez-moi de vous donner un exemple. Le Dr Tony Yaksh est l'une des autorités mondiales dans le domaine de la gestion de la douleur. Il a acquis ses compétences en faisant une enquête sur les mécanismes de la douleur dans la moelle épinière. Aujourd'hui, des millions de gens partout dans le monde profitent de l'application de ses compétences à diverses étapes de la gestion de la douleur. La recherche peut porter sur les soins à donner aux personnes souffrant de maladies mortelles, mais, heureusement, les maladies mortelles d'hier peuvent aujourd'hui être traitées et parfois évitées.

À l'époque où j'ai obtenu mon diplôme, il y avait une grave épidémie de polio à Winnipeg. Depuis dix ans, il n'y a plus de polio en Amérique du Nord. Quand j'ai terminé mes études, la gestion des patients atteints de polio en phase terminale posait un énorme problème. Comment peut-on traiter des patients branchés sur des poumons d'acier de façon chronique et sur de longues périodes?



I am here to tell you today that all of us observed the anguish of Sue Rodriguez confronting Lou Gehrig's disease, amyotrophic lateral sclerosis. The mechanisms of the etiology that lead to the loss of the same kinds of nerve cells that were destroyed by the polio virus are, in fact, affected by Lou Gehrig's disease. In my view, we are not far from the day when, rather than being focused on how to manage and support those who suffer inexorably leading to death from Lou Gehrig's disease, we will see that turned around by prevention or therapies. It is a similar situation for AIDS. Just a few years ago, it was inevitably a death sentence. Today, it is in many cases still a very difficult illness, but in fact it is becoming a chronic care issue as opposed to a terminal illness.

End-of-life issues have many expressions and the tempo and style of those expressions are variable. Science is a continuum, an endless frontier, where all the insights and tools, from the most fundamental knowledge about molecules to its application to the research, the social sciences, sociology of communities, impact on the agenda.

I looked carefully at the situation five years ago, when you issued your report, and compared it to today, where we see a substantial increase in investments. We chose at that time to broaden our research portfolio. Today, \$16 million is committed by MRC to literally hundreds of projects in support of end-of-life care, many of them, of course, focused on pain. Let me illustrate and offer a few examples: In psychiatric dimensions of palliative care, you heard from Dr. Chochinov, who raised and touched upon some of the same issues that you heard about today from Professor Mishara; quality of life following admission to palliative units, Dr. Cohen from McGill; quality of life and psychosocial impact of chronic disease; evaluation of chronic pain; self-management programs; pain in children, a program undertaken by Professor McGrath, who is also one of Canada's distinguished scientists, funded by the MRC.

I am also here to say that palliative care research is underfunded. For research to flourish, you need four essential elements. You need people, and Dr. MacDonald spoke about that. The Canadian Palliative Care Association has made the point that we need to build capacity. We need to provide and invest in people, because no amount of money thrown at a problem, particularly in research, will lead to helpful solutions if there are not people who are able and capable of using that money carefully and appropriately. You need facilities. We heard again about a supportive environment from Dr. MacDonald. Medical faculties seem not to appreciate and invest adequately. It again indicates that no one organization or institution can in fact provide all the solutions.

Je suis venu vous dire aujourd'hui que nous avons tous observé l'angoisse de Sue Rodriguez dans sa lutte contre la maladie de Lou Gehrig, la sclérose latérale amyotrophique. Les mécanismes qui entraînent la perte des cellules nerveuses sont en fait les mêmes pour le virus de la polio et la maladie de Lou Gehrig. À mon avis, nous pourrions bientôt cesser de nous concentrer sur l'aide à offrir aux patients atteints des souffrances qui mènent inexorablement à la mort provoquée par la maladie de Lou Gehrig pour nous tourner vers la prévention ou la thérapie. Il en va de même pour le sida. Il y a quelques années, cette maladie correspondait à une sentence de mort inévitable. Aujourd'hui, c'est encore dans bien des cas une maladie très grave, mais on la considère maintenant comme une maladie chronique plutôt que comme une mortelle.

Les questions relatives à la fin de la vie peuvent se manifester à des rythmes et selon des styles qui varient. La science est un continuum, un milieu sans frontière, dans lequel toutes les compétences et tous les outils, de la connaissance la plus fondamentale au sujet des molécules jusqu'à son application dans la recherche, les sciences sociales, la sociologie des collectivités, ont leur importance.

J'ai comparé la situation qui prévalait il y a cinq ans, quand vous avez produit votre rapport, à celle d'aujourd'hui. Nous constatons qu'il y a aujourd'hui une augmentation considérable des investissements. Il y a cinq ans, nous avons choisi d'étendre notre portefeuille de recherche. Aujourd'hui, le CRM verse 16 millions de dollars à des centaines de projets dans le domaine des soins en fin de vie; bon nombre de ces projets portent bien sûr sur la douleur. Permettez-moi de vous donner quelques exemples. Pour ce qui est des aspects psychiatriques des soins palliatifs, vous avez entendu le témoignage du Dr Chochinov, qui a discuté des aspects traités aujourd'hui par M. Mishara; le Dr Cohen, de l'Université McGill, étudie la qualité de vie du patient après son admission dans les unités de soins palliatifs; il y a aussi d'autres études sur la qualité de vie des patients atteints de maladies chroniques et sur les effets psychosociaux de ces maladies, sur l'évaluation de la douleur chronique, sur les programmes d'autogestion; Le professeur McGrath, un éminent scientifique canadien, a entrepris un programme de recherche sur la douleur chez les enfants, qui est financé par le CRM.

Je suis également venu témoigner de ce que la recherche en soins palliatifs n'est pas suffisamment financée. Pour être florissante, la recherche a besoin de quatre éléments essentiels. Il faut des chercheurs, comme le Dr MacDonald a dit. L'Association canadienne des soins palliatifs a fait valoir qu'il faut accroître nos ressources dans ce domaine. Il faut investir dans nos chercheurs, car on ne saura trouver de solutions utiles, quelles que soient les sommes d'argent investies, si nous n'avons pas des chercheurs capables d'utiliser cet argent convenablement. Il faut également des installations. Le Dr MacDonald a également parlé d'un milieu qui soutienne la recherche. Les facultés de médecine ne semblent pas comprendre la situation et investir suffisamment. Cela montre encore une fois qu'aucun organisme ou établissement ne peut à lui seul fournir toutes les solutions.



I am here also tell you that MRC has established a first-step program with the Canadian Palliative Care Association to build partnerships and to seek joint funding for individuals eager to embark on a career in this area. It is the first program of its kind.

I am also here to tell you that I think we are on the threshold of a whole new organizational, institutional approach — a modernized health research enterprise in this country that will be built once Bill C-13 is in place. It will create the Canadian Institutes of Health Research, which have as their most fundamental goal and objective, building an environment that is internationally competitive. The Prime Minister has said Canada must be a place where new knowledge in its fullest expression is created, from the most fundamental to the most applied. We need to see an integrated vision for health research, and attention being paid not only to fundamental science, but to its application, translation, adoption and dissemination, for the benefit of Canadians.

There is an opportunity, in this new structure, for organizations like the Canadian Palliative Care Association to have systematic input into priority setting. The Canadian Institutes of Health Research will have the capacity to invest strategically in a way that the MRC was unable to do. The National Health Research and Development Program, one of the components of Health Canada, will be incorporated into the Canadian Institutes for Health Research, and that whole area will become part of their portfolio, as will MRC's.

The transitional programs that have already begun with the new funding provided by the government will again provide new opportunities. One of those is the Community Alliances for Health Research, where organizations like the Canadian Palliative Care Association, in partnership with researchers, can put forward ideas and proposals that can be supported by the Canadian Institutes for Health Research.

I look forward to a new era, a new opportunity, where the important issues that will affect us all very intensely and personally at some stage in our lives, will be more appropriately addressed with knowledge generated by greater investment in more focused research than has ever been the case; and where there will be encouragement of an interdisciplinary, integrative health research environment developed through the CIHR. I look forward to seeing that bill move forward from the House to the Senate and ultimately adopted and proclaimed.

**The Chairman:** Our last presenter this morning is Mr. Russel Ogden, who also appeared before us in our first consideration of this significant issue.

**Mr. Russel Ogden:** Honourable senators, I thank you for the invitation to speak with you this morning. You may recall that when I appeared over five years ago, I called for research into the illegal behaviours of assisted suicide and euthanasia. Therefore I was especially pleased that your report "Of Life and Death"

En collaboration avec l'Association canadienne des soins palliatifs, le CRM a mis sur pied un programme de départ visant à établir des partenariats et à trouver des sources de financement mixtes pour les personnes qui souhaitent se lancer dans une carrière dans ce domaine. C'est le premier programme de ce genre.

Nous sommes sur le point d'adopter au Canada une nouvelle approche en matière d'organisation et d'établissement — une entreprise plus moderne de recherche en matière de santé, une fois que le projet de loi C-13 sera appliqué. Ce projet de loi entraînera la création des Instituts de recherche en santé du Canada, dont l'objectif le plus fondamental est de créer un climat compétitif à l'échelle internationale. Le premier ministre a déclaré que le Canada doit être un pays de découverte de nouvelles connaissances, de la plus fondamentale à la plus appliquée. Il faut mettre en place une vision intégrée de la recherche en matière de santé et ne pas se concentrer seulement sur la recherche fondamentale, mais aussi sur l'application de la science, sa concrétisation, son adoption et sa diffusion, pour le plus grand profit de tous les Canadiens.

Dans cette nouvelle structure, les organismes comme l'Association canadienne des soins palliatifs auront l'occasion de participer systématiquement à l'établissement de priorités. Les Instituts de recherche en santé du Canada pourront, contrairement au CRM, faire des investissements stratégiques. Le Programme national de recherche et de développement en matière de santé, qui relève de Santé Canada, sera intégré aux Instituts de recherche en santé du Canada, et tout ce domaine, de même que le CRM, fera partie du portefeuille des instituts.

Les programmes de transition, qui ont déjà commencé à être mis en oeuvre grâce au nouveau financement fourni par le gouvernement, offriront eux aussi de nouvelles possibilités. Entre autres, les Alliances communautaires pour la recherche en santé permettront à des organismes comme l'Association canadienne des soins palliatifs de travailler en partenariat avec les chercheurs et de faire des propositions qui pourront être appuyées par les Instituts de recherche en santé du Canada.

J'ai hâte que nous entamions une nouvelle ère, que nous ayons de nouvelles possibilités qui nous permettront de mieux traiter les questions importantes qui nous touchent tous intensément et personnellement à un moment donné de notre vie, grâce aux connaissances que produiront des investissements plus grands dans des recherches plus ciblées que jamais. On encouragera la recherche intégrée et pluridisciplinaire en santé dans le climat créé au moyen des ISRC. J'ai hâte que le projet de loi soit envoyé au Sénat par la Chambre des communes, qu'il soit adopté et proclamé.

**La présidente:** Notre dernier témoin de ce matin est M. Russel Ogden, qui a également comparu devant nous lorsque nous avons étudié pour la première fois cette question importante.

**M. Russel Ogden:** Honorables sénateurs, merci de votre invitation à venir vous rencontrer ce matin. Vous vous souviendrez peut-être que lorsque j'ai comparu devant vous, il y a cinq ans, j'avais réclamé que soient effectuées des recherches sur les comportements illégaux que sont l'aide au suicide et l'euthanasie.

recommended an investigation into the frequency of requests for assisted suicide and voluntary euthanasia, the reasons underlying such requests, and whether there were alternatives acceptable to those who make these kinds of requests.

I would like to be clear that I am not here to discuss whether illegal death is right or wrong. My interest as a researcher is in understanding why some people ask to be killed and why some people agree to help them to die. I believe that you will agree that these questions are of fundamental importance to end-of-life care and that they also have obvious relevance to Canadian criminal law.

As a researcher, I would like to talk about the kinds of barriers that I have encountered in trying to conduct the very sort of research that "Of Life and Death" recommended five years ago. I suggest to you that without designated funding, and without explicit governmental support for such research, it is unlikely that academic institutions will help us get much closer to answering the research questions that were posed in Chapters VII and VIII of "Of Life and Death".

In my written brief in 1994, I suggested that inquiries into assisted death issues needed to be supported by some form of protection, perhaps by the Minister of Justice. You might recall that when I spoke with you then, I had just completed an investigation into the "underground" phenomenon of assisted death amongst persons with HIV.

When I first appeared before the Senate committee, that study was a matter of ongoing concern. It was the subject of an inquest before the Vancouver regional coroner's office. In an effort to learn more about a woman who had been suffocated after a failed assisted suicide, the Vancouver regional coroner sought to compel me to disclose confidential information that I had obtained during the course of that research. I refused to reveal the information because it would have undermined the confidential relationship that was central to the research in the first instance. Obviously, I could never have learned about secret, illegal acts of assisted death if people thought that they would be brought before a court as a result.

Ultimately, the coroner determined that I had a public interest privilege to protect the privacy of my research participants. The common law test that was applied in this case is known as the *Wigmore* criteria. That is a case-by-case test. According to recent legal opinion from University of British Columbia law professors, Michael Jackson and Marilyn MacCrimmon, the *Wigmore* criteria may be the best option for researchers who wish to challenge the ability of a court to force the disclosure of confidential research information.

When I was defending the privacy of my research participants before the coroner, I argued that the integrity of the research enterprise demanded that researchers not be perceived as an arm of the criminal justice system. Unfortunately, the administration at Simon Fraser University, where I conducted the research, did not

J'ai donc été très heureux que dans votre rapport, «De la vie et de la mort», vous recommandiez que soit fait un examen de la fréquence des demandes de suicide assisté et d'euthanasie, des raisons pour lesquelles ces demandes sont faites et des solutions de rechange acceptables pour ceux qui présentent ces demandes.

Je ne suis pas venu discuter si la mort illégale est bien ou mal. En tant que chercheur, ce qui m'intéresse, c'est de comprendre pourquoi certaines personnes demandent à être tuées et pourquoi d'autres personnes acceptent de les aider à mourir. Vous conviendrez que ce sont des questions fondamentales pour les soins en fin de vie et que ces questions sont également pertinentes au droit pénal canadien.

En tant que chercheur, je vais vous parler des obstacles auxquels j'ai été confronté lorsque j'ai essayé de faire le genre de recherches que préconisait votre rapport il y a cinq ans. Je dis que sans financement réservé à cette fin et sans aide explicite des gouvernements à de telles recherches, il est peu probable que les établissements d'enseignement supérieur nous aident à trouver les réponses aux questions posées dans les chapitres VII et VIII du rapport «De la vie et de la mort».

Dans le mémoire que je vous avais présenté en 1994, je disais que les recherches sur les questions relatives à l'aide à la mort devaient être assorties d'une forme quelconque de protection, fournie peut-être par le ministre de la Justice. Vous vous souviendrez qu'à cette époque, je venais de terminer une enquête sur le phénomène «clandestin» de l'aide à la mort chez les personnes atteintes du VIH.

Lors de ma première comparution devant le comité du Sénat, cette étude a suscité de nombreuses préoccupations persistantes. Son sujet avait fait l'objet d'une enquête du bureau du coroner régional de Vancouver. Afin d'en savoir davantage sur le cas d'une femme qui avait été asphyxiée après avoir tenté de se suicider avec l'aide de quelqu'un, le coroner régional de Vancouver avait voulu m'obliger à divulguer des renseignements confidentiels que j'avais obtenus dans le cadre de cette recherche. Je lui ai opposé un refus car en divulguant ces renseignements, j'aurais miné le secret professionnel qui était essentiel à ma recherche. Évidemment, je n'aurais jamais pu être informé d'actes secrets et illégaux d'aide au suicide si mes répondants craignaient d'être ensuite entraînés devant les tribunaux.

En fin de compte, le coroner a décidé que je jouissais du privilège conforme à l'intérêt public de pouvoir protéger la vie privée des répondants à ma recherche. Le critère de common law appliqué dans ce cas est celui qu'on appelle le critère *Wigmore*. Ce critère s'applique au cas par cas. D'après les opinions juridiques rendues récemment par deux professeurs de droit de l'Université de la Colombie-Britannique, Michael Jackson et Marilyn McCrimmon, le critère *Wigmore* est peut-être la meilleure solution pour les chercheurs qui souhaitent contester le pouvoir d'un tribunal de les obliger à révéler des renseignements confidentiels obtenus dans le cadre d'une recherche.

Pour défendre la vie privée de mes répondants devant le coroner, j'ai fait valoir que l'intégrité d'une recherche exigeait que les chercheurs ne soient pas perçus comme des outils du système de droit pénal. Malheureusement, l'administration de l'université Simon Fraser, où je réalisais ma recherche, ne partageait pas les



share the same concerns for academic freedom and declined the opportunity to support the argument in the coroner's court. This sent a negative message to researchers who investigate illegal behaviours. Indeed, the criminology school at SFU took steps to warn all prospective graduate students that they could not count on support from the university administration if complications were to arise in the course of their research into sensitive behaviours. As you can imagine, that altered the nature and scope of graduate research at that institution, and perhaps elsewhere. It was not until four years and a day after the coroner's ruling that the Simon Fraser University president issued an apology and stated that the university had been wrong in its failure to defend freedom of academic inquiry.

Nevertheless, there is still widespread concern that the university does not wish to facilitate research into highly sensitive topics such as euthanasia, prostitution, or illegal drug use. I understand that the current climate is such that there is no way that a graduate student or a faculty member would be permitted to conduct research under the protocol that it had permitted me. Specifically, the university no longer allows researchers to give assurances of absolute confidentiality to their participants. This is tragic because it is stifling empirical inquiry into critical social policy areas. It stifles the very research that you have called for, into requests for euthanasia and assisted suicide.

You heard testimony earlier from the NHRDP that there has been funding available for end-of-life research in the form of "synthesis" papers, and that this is a very safe way to do research. It seems to be the new direction for sanitized and safe academic inquiry. However, I submit that evaluation research of this kind, while it is very useful for bringing together what we already know, cannot inform us in the same way as direct empirical investigation.

The institutional barriers to conducting research into assisted death are not unique to Canada. After the "Of Life and Death" report recommended further research on this topic, I took up Ph.D. studies at Exeter University in England. There I completed more than 100 interviews in four countries: England, the Netherlands, the U.S.A., and Canada. Again, I was researching end-of-life issues with respect to voluntary euthanasia and assisted suicide. Near the end of that field research, it was discovered that the Chair of the departmental ethics committee had secretly altered the original ethical approval and the statement of university support for sustaining confidentiality in the research. He insisted that the ethical approval of the research had not been, "revised, rescinded, or countermanded". However, that was a complete misrepresentation. The informed consent of all my research participants was undermined and the research conditions under which I thought I was working never really existed.

mêmes préoccupations que moi en matière de liberté des chercheurs et elle a refusé d'appuyer mes arguments devant le coroner. Cela a eu pour effet de décourager les chercheurs qui enquêtent sur des comportements illégaux. En fait, l'école de criminologie de l'université a pris la peine d'informer tous les étudiants de deuxième et troisième cycle qu'ils ne pouvaient compter sur l'appui de l'administration de l'université en cas de complications dans leurs recherches sur des comportements délicats. Comme vous le pensez bien, cela a modifié la nature et la portée des recherches effectuées par les étudiants dans cette université, et peut-être ailleurs aussi. Il a fallu attendre quatre ans et un jour après la décision du coroner pour que le président de l'Université Simon Fraser présente des excuses et déclare que l'université avait eu tort en refusant de défendre la liberté de la recherche universitaire.

Néanmoins, bien des gens s'inquiètent encore de ce que l'université n'a pas l'intention de faciliter la recherche dans des sujets très délicats comme l'euthanasie, la prostitution ou la consommation de drogues illégales. Je crois savoir que dans l'état actuel des choses, les étudiants de deuxième et troisième cycle et les membres du corps enseignant n'ont pas l'autorisation de faire des recherches selon le protocole qui s'appliquait à la mienne. Plus particulièrement, l'université ne permet plus aux chercheurs de garantir à leurs répondants qu'ils seront protégés par le secret professionnel. Cette situation est tragique, car elle nuit à la recherche empirique dans des domaines essentiels de politique sociale. Elle nuit à la recherche que vous avez réclamée, aux recherches sur l'euthanasie et l'aide au suicide.

Les représentants du PNRDS vous ont dit précédemment qu'un financement avait été consenti à la recherche sur les soins en fin de vie effectuée sous forme de rapports de synthèse. C'est un type de recherche qui ne présente pas de risque. Il semble que la nouvelle orientation soit de faire ce genre de recherches aseptisées et sans danger. Toutefois, je soumets que même si les recherches évaluatives de ce genre peuvent être très utiles, car elles permettent d'examiner ce que nous savons déjà, elles ne peuvent nous fournir autant d'informations que la recherche empirique directe.

Mais il n'y a pas qu'au Canada que des obstacles institutionnels rendent difficiles la recherche sur l'aide à la mort. Après que le rapport «De la vie et de la mort» a recommandé une augmentation de la recherche dans ce domaine, j'ai entrepris des études de doctorat à l'Université d'Exeter, en Angleterre. J'y ai réalisé plus de 100 entrevues dans quatre pays: l'Angleterre, les Pays-Bas, les États-Unis et le Canada. Je faisais encore une fois des recherches sur les questions liées à la fin de la vie, plus particulièrement à l'euthanasie et à l'aide au suicide. Vers la fin de ma recherche sur le terrain, on a découvert que le président du Comité d'éthique du département avait en secret modifié les conditions initiales d'approbation éthique et la déclaration d'appui de l'université quant au caractère confidentiel de la recherche. Il a insisté sur le fait que l'approbation éthique de la recherche n'avait pas été modifiée ou annulée. C'était toutefois complètement faux. Ces mesures avaient pour effet de miner le consentement éclairé de tous les participants à ma recherche, et les conditions dans



Exeter University held an inquiry that found "the ethical approval of Ph.D. research was mishandled and demonstrated serious incompetence and subsequent misjudgment by the department". It found that the supervision of the research was both inadequate and unsatisfactory. I use these words freely because they are the language of the university's own report, but to this day, Exeter University still refuses to clarify the true nature of the ethical approval of that research, despite a clear directive from its own university senate committee of academic inquiry that it should do so. This kind of institutional inertia has grave consequences for research and researcher morale.

Therefore, I am very sorry to tell you that although my research fell squarely within the scope of the "Of Life and Death" report's recommendations from chapters VII and VIII, I have not yet found a way to revive it. The message here is that academic institutions do not, at this time, provide the necessary fertile environment for implementing the Senate committee's recommendations for research into assisted suicide and voluntary euthanasia.

I would like to suggest some potential solutions to this problem. First, there needs to be independent funding targeted at the research recommendations in chapters VII and VIII of the "Of Life and Death" report. This funding should be open to qualified researchers who are not necessarily working within an institutional setting. Second, there needs to be some kind of protection for participants and researchers in order to facilitate the collection of data and its security.

As I said in 1994, and I repeat, perhaps the Minister of Justice could authorize confidentiality provisions. These provisions could be similar to those that are already available to Statistics Canada researchers. Another alternative protection might be the equivalent of what are known as "privacy certificates", which are available in the United States through the U.S. Department of Justice, or there might be something known as a "confidentiality certificate". This is available through the Department of Health and Human Services in the United States. The Senate should explore the possibility of implementing these kinds of protections for researchers in Canada.

Finally, I should like to briefly address the "Of Life and Death" report's unanimous recommendation that voluntary euthanasia and counselling assisted suicide remain criminal offences. As I stated earlier, I am not here to debate the right or the wrong of these crimes. However, I do wish to inform the committee of some new developments within the underground assisted death movement.

I call this movement a "deathing counterculture" because its constituents see themselves as providing what they call "deathing services", much the way a midwife or a physician might participate in birthing. This so-called "deathing counterculture" is organized and sophisticated. You heard from Dr. Young about Jack Kevorkian broadening the scope of his activities. This

lesquelles je croyais réaliser ma recherche n'avaient jamais vraiment existé.

L'Université d'Exeter a tenu une enquête qui a constaté que l'approbation éthique de ma recherche de doctorat avait été mal effectuée et révélait un problème grave d'incompétence et de manque de jugement au sein du département. L'enquête a révélé que la supervision de la recherche était inadéquate et insatisfaisante. Je me sens bien à l'aise d'utiliser ces termes puisque c'est ce qu'on dit dans le rapport de l'université elle-même. Mais jusqu'à présent, l'Université d'Exeter n'a toujours pas accepté de préciser quelle était l'approbation éthique réelle de cette recherche, malgré les directives claires que lui a données son propre comité d'enquête. Une telle inertie institutionnelle a des conséquences graves pour la recherche et le moral des chercheurs.

C'est donc avec regret que je vous signale que même si ma recherche correspondait exactement aux recommandations des chapitres VII et VIII de votre rapport, je n'ai toujours pas trouvé le moyen de la continuer. Mon message, c'est qu'à l'heure actuelle, les établissements d'enseignement supérieur n'offrent pas un milieu suffisamment fertile pour mettre en oeuvre les recommandations du comité du Sénat en matière de recherche sur l'aide au suicide et l'euthanasie.

Permettez-moi de proposer quelques solutions à ce problème. Tout d'abord, il faut prévoir un financement indépendant des recherches correspondant aux recommandations des chapitres VII et VIII de votre rapport. Ce financement devrait être offert à des chercheurs qualifiés qui ne travaillent pas nécessairement dans des établissements. Deuxièmement, il faut offrir aux participants et aux chercheurs une protection quelconque de façon à faciliter la collecte de données et la conservation sans danger de ces données.

Comme je le disais en 1994, et je le répète, le ministre de la Justice pourrait peut-être prendre des dispositions pour que ces renseignements soient considérés comme confidentiels. Ces dispositions pourraient être semblables à celles qui protègent déjà les chercheurs de Statistique Canada. Comme autre mesure de protection, on pourrait instaurer un régime de «certificats de protection de la vie privée», comme il en existe aux États-Unis, par l'entremise du ministère de la Justice. Ou bien, on pourrait distribuer des «certificats de confidentialité». Ces documents sont distribués par le Department of Health and Human Services des États-Unis. Le Sénat devrait envisager la possibilité de mettre en place de tels régimes de protection à l'intention des chercheurs canadiens.

Enfin, permettez-moi de parler brièvement de la recommandation unanime du rapport «De la vie et de la mort» visant à ce que l'euthanasie et l'aide au suicide continuent d'être des actes criminels. Comme je l'ai déjà dit, je ne suis pas ici pour débattre du caractère moral de ces actes. Je tiens toutefois à informer le comité de certains nouveaux développements au sein du mouvement clandestin d'aide au suicide.

C'est un mouvement que j'ai baptisé «contre-culture de la mort», car ses membres estiment qu'ils offrent des «services d'aide à la mort», de la même façon que les sages-femmes ou les médecins aident aux naissances. Cette contre-culture de la mort est organisée et très au point. Le Dr Young vous a dit que Jack Kevorkian avait élargi le cadre de ses activités. Il en va de même

movement is not much different. Its members have pioneered what they call the “NuTech” initiative. This is a technological imperative to develop non-pharmaceutical devices that bring about rapid and painless death. It appears that they have achieved this goal because the movement has produced an array of devices that can cause painless death in a matter of minutes. They are relatively easy to construct and require none of the substances or precursors that, you heard earlier, are under the jurisdiction of the Canadian Therapeutic Products Program.

Indeed, most of the necessary components for these devices can be purchased at large retail outlets. As these NuTech devices require no injections and no lethal doses of medication, there is no “smoking gun” to suggest any foul play. To be sure, numerous field trials by this organized, underground movement suggest that the true cause of death from these “deathing” devices is consistently undetected and overlooked.

I bring this to your attention because the underground technological imperative to create non-pharmaceutical methods for assisted death raises serious challenges to the health care professions, legislators, and policymakers. The NuTech devices raise many of the same issues as the morning-after pill because they generate distance between patients and their health care providers when it comes to discussion of end-of-life decisions.

This underground movement is virtually unstoppable and it appears to be a growth industry. I have no solutions for you on that. This is an entrepreneurial response to what are seen as barriers to legal medically assisted death. It is an outcome of prohibition. It is characteristic of what we have already seen many times with respect to other taboo behaviours. I raise this because we need to consider the consequences of choosing prohibition and social control of assisted suicide and voluntary euthanasia.

**Senator Beaudoin:** My question is addressed to Dr. Young. You said that at least some sections of the Criminal Code have to be clarified?

**Dr. Young:** Yes, sir.

**Senator Beaudoin:** It is my understanding that you were addressing at least two areas, namely, withholding of treatment and refusal of treatment. Is that what you are suggesting, in those two fields, or in other fields?

**Dr. Young:** I would establish a separate Criminal Code section that defines an offence called “euthanasia” and the punishments for it.

The problem the courts run into when there is a case that may contravene the current Criminal Code is that there is a huge debate among Crown counsel and police as to what charges should be laid. Do we lay first or second degree murder charges or manslaughter charges? Most commonly, in Ontario, we have ended up settling on “administration of a noxious substance,” which is a long way from what was originally intended by that section.

de ce mouvement. Ses membres ont lancé ce qu'ils appellent l'initiative «technologie nouvelle». Le but de cette initiative est de mettre au point des moyens non pharmaceutiques de provoquer une mort rapide et sans douleur. Il semble que cet objectif ait été atteint, car le mouvement a produit toute une gamme de moyens qui peuvent provoquer la mort en quelques minutes. Il s'agit de dispositifs relativement faciles à construire et qui ne nécessitent ni les substances ni les précurseurs dont on vous a dit précédemment qu'ils relevaient du Programme des produits thérapeutiques du Canada.

Enfin, la plupart des éléments nécessaires à ces appareils peuvent être achetés dans des grands magasins de détail. Puisque ces appareils de nouvelle technologie ne nécessitent ni injections ni doses mortelles de médicaments, il n'est pas possible de retrouver une «arme du crime». D'après les nombreux essais organisés par ce mouvement clandestin, lorsque ces appareils sont utilisés, la cause réelle du décès passe toujours inaperçue.

Je vous signale que l'objectif clandestin de mettre au point des méthodes non pharmaceutiques d'aide à la mort cause des problèmes graves aux professionnels de la santé, aux législateurs et à ceux qui élaborent les politiques. Ces appareils de nouvelle technologie suscitent bon nombre des mêmes problèmes que la pilule du lendemain, car ils créent un écart entre les patients et leurs soignants, quand il faut discuter des décisions à prendre en matière de fin de vie.

Il est à peu près impossible de mettre fin à ce mouvement clandestin et il semble qu'il constitue une industrie en pleine croissance. Je n'ai pas de solutions à vous proposer à ce sujet. Il s'agit d'une réaction entrepreneuriale à ce qu'on considère être les obstacles à l'aide médicale légale au suicide. C'est le résultat d'une interdiction. Il s'agit d'une caractéristique qui a déjà été constatée à maintes reprises dans le cas d'autres comportements interdits. Si je le mentionne, c'est qu'il faut tenir compte des conséquences du choix de l'interdiction de l'aide au suicide et de l'euthanasie volontaire plutôt que d'autres options comme la réglementation et le contrôle social.

**Le sénateur Beaudoin:** Ma question s'adresse au Dr Young. Vous avez dit qu'il faudrait au moins préciser certains articles du Code criminel?

**Dr Young:** Oui, monsieur.

**Le sénateur Beaudoin:** Je crois savoir que vous parliez de deux domaines en particulier, plus précisément du retrait du traitement et de son refus. C'est bien dans ces domaines-là qu'il faudrait apporter ces précisions, ou dans d'autres?

**Dr Young:** Il faudrait créer un article distinct du Code criminel dans lequel on définirait le délit portant le nom d'euthanasie et les sanctions qui en découlent.

Le problème des tribunaux, lorsqu'ils examinent un cas qui va à l'encontre du Code criminel actuel, c'est que l'avocat de la Couronne et les policiers doivent longuement débattre des accusations qui devraient être portées. Doit-on porter des accusations de meurtre au second degré ou d'homicide? Dans la plupart des cas, en Ontario, on a fini par porter des accusations «d'administration d'une substance nocive», qui est loin de correspondre à l'esprit de cette disposition.



Along the same lines, the courts have wrestled with what is reasonable punishment. If the offence were clearly enshrined in the Criminal Code, including the range of punishments, that would then become much less of a problem and would add clarity to the debate. The definition of an offence can change and I am not arguing for or against what it should be. I am simply arguing that there should be clarity.

One important element in keeping a rein on activities is clearly defining the line and some ability to adhere to it. That is the problem we run into now.

**Senator Beaudoin:** At the time of the previous report, the name of Sue Rodriguez was often in the news. The ruling at that time covered the question of assisted suicide to a certain extent and, indirectly perhaps, euthanasia.

The previous report contained unanimity in at least three or four fields: palliative care, withholding of instruments, refusal of treatment, and some others. The purpose of this committee is to give effect to those subjects on which there was unanimous agreement amongst senators.

The Chair of a group of doctors in Canada said that we do not need any change in the legislation. He is from Montreal.

**The Chairman:** The representatives from the Royal College of Physicians and Surgeons did not agree with a need for new legislation, although the Canadian Medical Association holds an opposite view.

**Senator Beaudoin:** They said that we do not need to change the Criminal Code. I was surprised by their comment, but that is an interesting proposition.

You said that you are in favour of modifying or amending the Criminal Code. I come to the conclusion that we need more clarity in the code for caregivers — doctors, nurses and so on. They need to know what they have a right to do and what is not legal.

At present, we are not dealing with euthanasia and assisted suicide per se, but rather with all the other aspects of the first report. Even in that field, I am inclined to think that we should not rely only on jurisprudence, be it in Quebec, Ontario, or other provinces. We need a clearer Criminal Code on those subjects.

The Criminal Code is amended often. It is a difficult part of the law, but a very important one. On the withholding of instruments and the refusal of treatment, perhaps we may improve the Criminal Code in those two fields.

I do not see many problems in the field of palliative care, as criminal law is not involved in that. In what way do you think we should amend the Criminal Code, for the purposes of this committee?

**Dr. Young:** The area I spoke about falls within your mandate. Justice Sopinka stated in his ruling that there is a clear point at which someone is committing a criminal act. The problem is in interpreting that point. Anything we can do to add clarity to that

Parallèlement, les tribunaux ont essayé de déterminer quelle serait une sanction raisonnable dans ces cas. Si l'acte criminel était clairement inclus dans le Code criminel, y compris la gamme des sanctions qui peuvent être imposées, le problème serait beaucoup moins grand et le débat en serait éclairé. La définition des délits peut être modifiée et je ne veux pas discuter de ce que devrait être cette définition. Je dis simplement qu'il faudrait le préciser.

Lorsqu'on veut contrôler une activité, il est important entre autres d'établir les limites et les moyens de les respecter. C'est le problème qui se pose, à l'heure actuelle.

**Le sénateur Beaudoin:** Lorsque le rapport précédent a été publié, le nom de Sue Rodriguez faisait souvent la manchette. À cette époque, la décision rendue traitait un peu la question de l'aide au suicide et indirectement peut-être, de l'euthanasie.

Le rapport précédent était unanime dans au moins trois ou quatre domaines: les soins palliatifs, le débranchement des appareils, le refus de traitement, et quelques autres. Le but de notre comité est de revoir les sujets sur lesquels les sénateurs s'étaient entendus de façon unanime.

Le président d'un groupe de médecins canadiens a déclaré qu'il ne faut rien changer aux lois. Il vient de Montréal.

**La présidente:** Les représentants du Collège royal des médecins et chirurgiens ont dit qu'il n'était pas nécessaire d'adopter une nouvelle loi, même si l'Association médicale canadienne était d'avis contraire.

**Le sénateur Beaudoin:** Ils ont dit qu'il n'est pas nécessaire de modifier le Code criminel. J'ai été étonné de cette observation, mais c'est une proposition intéressante.

Vous avez dit que vous êtes en faveur de modifications au Code criminel. J'en conclus qu'il faut préciser les dispositions du Code à l'intention des soignants, médecins, infirmiers-infirmières, et cetera. Les soignants doivent savoir ce qu'ils ont le droit de faire et ce qui est illégal.

À l'heure actuelle, nous ne traitons pas de l'euthanasie et de l'aide au suicide en soi, mais plutôt de tous les autres aspects du premier rapport. Même dans ces domaines, je suis enclin à croire qu'il ne faut pas seulement se fonder sur la jurisprudence, que ce soit celle du Québec, de l'Ontario ou d'autres provinces. Ce qu'il nous faut, c'est un Code criminel plus précis dans ces domaines.

Le Code criminel est souvent modifié. C'est un aspect difficile du droit, mais il est néanmoins très important. Il faudrait peut-être améliorer les dispositions du Code criminel au sujet du débranchement des instruments et du refus de traitement.

Je ne vois pas de gros problèmes dans le domaine des soins palliatifs puisque cela ne touche pas le droit pénal. De quelle façon pensez-vous que nous devrions modifier le Code criminel, aux fins de ce comité?

**Dr. Young:** Le domaine dont je parlais relève de votre mandat. Le juge Sopinka a déclaré dans sa décision qu'il était évident qu'à un certain moment quelqu'un commet un acte criminel. Le problème est d'interpréter à quel moment cela arrive. Tout ce que



would ensure that people understand the concept has the effect of promoting palliative care as well.

The changes I am proposing add clarity. I am not asking that any lines be changed. I simply ask for clarity. I think a separate Criminal Code definition of euthanasia and a set of punishments would go a long way toward that clarity.

I knew that there was some debate among the physician groups, but they are not dealing with the subject every day on a practical level, and I am. It would be very useful if the subject were better defined, which would also serve the current interests of this committee.

**Senator Beaudoin:** We have two schools of thought here. Some people say, "Leave it to the doctors. Leave it to the courts if there is a problem." Other people say, "Better criminal law will solve this problem." I am attracted by the second.

To leave everything to the courts, even if we do have a good judicial system, is not possible. We — the members of the Senate and the House of Commons — still have the obligation to make good laws. I am of that school. My impression is that we should, perhaps, in our report, make some propositions to that effect and not leave it entirely to doctors, nurses, and the courts, as they do in some countries. In this country, we should select the second school of thought.

You are dealing every day, as a coroner, with death. Your experience is very important to us. If you say that we need more guidelines, more information and better laws, I will buy that. I think that is the solution.

**Dr. Young:** I am always pleased when someone agrees with me. As someone who works in the justice system every day, I came to the conclusion long ago that the less left to that system the better. It is cumbersome and not the best way of resolving any issue.

**Senator Beaudoin:** I would not go that far, however, because I have a tremendous admiration for our judicial system.

**Dr. Young:** I do too, but it also causes lots of problems.

**Senator Beaudoin:** Supreme Court decisions over the past five years have told Parliament, "Do your job, and we will do ours." They do a fantastic job. The legislative and judicial branches of the state must do their work. That is all I am saying.

**Dr. Young:** I am suggesting that, even if clarity is added, the courts occasionally will have to act. The problem now is that there is not sufficient clarity. A lot of the cases and problems could be avoided by clarifying things. You will never eliminate the courts from the issue. However, it is much easier for the courts to act when there is a clear line, and it is then a question of whether or not behaviour crosses that line. Leaving too much to interpretation

nous pouvons faire pour clarifier les choses permettrait aux gens de comprendre que ce concept peut être utile également pour les soins palliatifs.

Les changements que je propose visent à clarifier des choses. Je ne demande pas qu'on change certains articles, je demande simplement que ce soit plus clair. Je pense qu'une définition distincte de l'euthanasie donnée dans le Code criminel ainsi qu'une série de peines pourraient faire beaucoup dans ce sens.

Je savais qu'il y avait un débat entre les groupes de médecins mais ils ne traitent pas de la question chaque jour sur plan pratique comme moi. Il serait très utile que la chose soit mieux définie et je crois que cela servirait aussi les intérêts actuels du comité.

**Le sénateur Beaudoin:** Il y a deux écoles de pensée à ce sujet. Il y en a qui disent: «Laissez les médecins décider. Laissez les tribunaux intervenir en cas de problème.» D'autres disent: «Ce problème peut être réglé en améliorant le droit pénal.» Je suis plus attiré par la seconde option.

Tout laisser aux tribunaux, même si nous avons un bon système judiciaire, n'est pas possible. Nous — sénateurs et députés — sommes tenus d'adopter de bonnes lois. C'est mon point de vue. J'ai l'impression que nous devrions peut-être dans notre rapport faire certaines propositions dans ce sens et ne pas laisser la question entièrement entre les mains des médecins, des infirmiers et infirmières et des tribunaux, comme cela se fait dans certains pays. Dans notre pays, nous devrions préférer la deuxième école de pensée.

En votre qualité de médecin légiste, vous avez quotidiennement affaire à la mort. Votre expérience est très importante pour nous. Si vous dites qu'il faut davantage de lignes directrices, davantage d'informations et de meilleures lois, je vous entends. Je crois que c'est en effet la solution.

**Dr. Young:** Cela me plaît toujours que quelqu'un soit d'accord avec moi. Comme je travaille quotidiennement dans le domaine de la justice, j'en suis arrivé à la conclusion il y a longtemps que moins on laisse de place à l'interprétation, mieux c'est. Sinon, c'est compliqué et ce n'est pas la meilleure façon de régler un problème.

**Le sénateur Beaudoin:** Je n'irai peut-être pas jusque-là parce que j'ai énormément d'admiration pour notre système judiciaire.

**Dr. Young:** Moi aussi, mais cela cause aussi des tas de problèmes.

**Le sénateur Beaudoin:** Les décisions de la Cour suprême ces cinq dernières années ont rappelé au Parlement qu'il devait faire son travail et qu'elle était prête à faire le sien. Elle fait un travail fantastique. Les pouvoirs législatif et judiciaire doivent l'un et l'autre faire leur travail. C'est tout ce que je veux dire.

**Dr. Young:** Je disais que même si l'on rendait les choses plus claires, les tribunaux devraient à l'occasion intervenir. Le problème, à l'heure actuelle, est que ce n'est pas suffisamment clair. On pourrait éviter beaucoup de cas et de problèmes en clarifiant les choses. On n'éliminera jamais le rôle des tribunaux. Toutefois, il est beaucoup plus facile pour les tribunaux d'agir lorsque les choses sont claires: il s'agit alors simplement de savoir

causes inconsistencies for physicians and nurses. Different practices can arise across the country because different people interpret the same law differently. I do not think that is healthy, particularly when those doing the interpreting are not trained in the law.

**The Chairman:** Dr. Young, would you say that, in the Province of Ontario, it is almost impossible to convict for euthanasia and assisted suicide?

**Dr. Young:** Certainly in our experience, it is extremely difficult. There is no offence called "euthanasia", so you are trying to fit a square peg into a round hole. We have had convictions for the administration of a noxious substance, but it was quite a square peg in a round hole at that point. Two of those cases went from first degree murder, all the way down past second degree, manslaughter, and assault, and into administration of a noxious substance. It was difficult and awkward, but, by the same token, the province felt that the actions were outside of the norm to a degree where they had to be dealt with in the courts. That was the best we could do.

**Senator Corbin:** Dr. Friesen, you alluded to underfunding of research in the field of palliative care. I presume you were talking about government funding. What private sources of funding are currently available? Are you aware of whether pharmaceutical companies, or other bodies of that nature, are doing any serious research respecting palliative care?

**Dr. Friesen:** The funding of research in Canada has four major contributing sectors: the federal government, the provincial governments, the voluntary sector, and then the private sector, or industry. The pharmaceutical industry is the largest single investor today, to the tune of about \$1 billion per year. Within that portfolio, there are many examples of research that impacts on end-of-life care issues. One of the major examples is AstraZeneca, which has set up not quite a world product mandate class, but close to it, in pain mechanisms, discoveries, and molecules, in Montreal. Why did they choose Montreal? It was because there are some very innovative researchers in Montreal who have made important new discoveries about molecules that could be developed for a whole new applicability in pain management.

The short answer to your question is yes, there is substantial private sector investment. My latest information is there might be 120 people engaged in that one effort in Montreal. It is only one example. There are a number of others like it — but not perhaps on the same scale.

There are also many clinical trials involving new therapeutic agents and products that are funded by the private sector. There are, of course, some more modest investments by local community foundations and volunteer groups. The most notable among those would be the support generated by the Canadian Cancer Society and the National Cancer Institute.

si un comportement représente ou non un abus. Laisser trop à l'interprétation des intervenants aboutit à certaines incohérences pour les médecins et les infirmiers et infirmières. Différentes pratiques peuvent être adoptées dans le pays parce que différentes personnes interprètent différemment la même loi. Je ne pense pas que cela soit sain, en particulier lorsque ceux qui interprètent la loi n'ont pas forcément reçu une formation juridique.

**La présidente:** Docteur Young, diriez-vous qu'en Ontario, il est presque impossible de condamner pour l'euthanasie et l'aide au suicide?

**Dr. Young:** Nous avons en effet constaté que c'est extrêmement difficile. Il n'y a pas d'infraction appelée «euthanasie», alors on essaie de faire l'impossible. On a eu des condamnations pour l'administration de substance délétère mais c'était vraiment mettre la pièce à côté du trou. Deux de ces cas sont allés de meurtre au premier degré à homicide involontaire, voies de fait et administration de substance délétère sans même passer par meurtre au second degré. C'était difficile et gênant mais, en même temps, la province estimait que ces actes avaient dépassé la norme à tel point qu'ils devaient être confiés aux tribunaux. C'est tout ce que nous pouvions faire.

**Le sénateur Corbin:** Docteur Friesen, vous avez fait allusion au sous-financement de la recherche en matière de soins palliatifs. Je suppose que vous parliez du financement public. Quelles sources de financement privées existe-t-il actuellement? Savez-vous si des compagnies pharmaceutiques, ou d'autres organismes de ce genre, font des recherches sérieuses à propos des soins palliatifs?

**Dr. Friesen:** Le financement de la recherche au Canada repose sur quatre grands piliers: le gouvernement fédéral, les gouvernements provinciaux, le secteur bénévole et le secteur privé ou l'industrie. L'industrie pharmaceutique est le plus gros investisseur aujourd'hui, un milliard de dollars environ par an. Dans ce portefeuille, il y a beaucoup d'exemples de recherche qui touche les questions des soins en fin de vie. Un des principaux exemples est AstraZeneca, qui s'est donné un mandat peut-être pas à l'échelle internationale, mais pas loin, pour la découverte de mécanismes et de molécules de contrôle de la douleur, à Montréal. Pourquoi Montréal? Parce qu'il y a certains chercheurs très novateurs à Montréal qui ont fait des découvertes importantes sur des molécules que l'on pourrait utiliser pour tout un éventail de modes de gestion de la douleur.

Je répondrai donc à votre question qu'il y a en effet d'importants investissements du secteur privé. D'après les derniers renseignements que j'ai, quelque 120 personnes sont engagées dans cet effort à Montréal. Ce n'est qu'un exemple. Il y en a d'autres semblables — peut-être pas toutefois à exactement la même échelle.

Il y a aussi beaucoup d'essais cliniques sur de nouveaux agents et produits thérapeutiques qui sont financés par le secteur privé. Il y a, évidemment, certains investissements plus modestes qui sont effectués par des fondations locales et des groupes à but non lucratif. Les plus remarquables sont ceux que la Société canadienne du cancer et la National Cancer Institute ont sollicités.



**Senator Corbin:** In terms of private involvement in this type of research, are the results generally available to the professional community at large, or is it restricted, confidential information because of considerations such as propriety rights, the development of medication, and so on? What is the score there?

**Dr. Friesen:** All the knowledge generated through research investments by the federal and provincial governments and voluntary agencies is in the public domain. I would guess that the knowledge generated with primary support from the private sector, to a considerable degree, emerges in the public domain rather more quickly than in the past. This is particularly so if there is a partnership initiative with the federal government, as in the case of the MRC. All of those research topics are published. The lists are available.

The barrier to application lies not so much in whether it is in the public or private domain, but rather in the dissemination and use of the new knowledge. It is being generated in ever greater amounts, with ever greater speed, so that even a practitioner who is trying to maintain his or her currency has difficulty absorbing all the new information that could be utilized to advantage.

One new trend is that more knowledgeable patients or clients more often than not now come armed with Internet-generated information that they have assembled. There is a more informed dialogue between the patient or client and the practitioner, in which the client will say, "Doctor, I have seen all this new information. Why are we using this medication versus that?" It is an interesting new aspect of professional practice, and in my view, it is probably a healthy one.

**Senator Corbin:** Dr. Young, to continue the exchange you had with Senator Beaudoin on clarifying certain things in the Criminal Code, I gather that you were not promoting murder for compassionate reasons?

**Dr. Young:** No. I am not saying there should be any change necessarily in the definition. I am saying that whatever definition we are using — and assuming we stay with the current definition — it should be clear in the law, with a clear Criminal Code offence that says "to go beyond this is euthanasia and here are the appropriate penalties for that".

**Senator Corbin:** Dr. Young, I would like to get your reactions to Mr. Ogden's comments about the organized, underground "death services". Does that pose a problem for you?

**Dr. Young:** It poses a large problem. I am aware, anecdotally, of the reports on this. In Ontario, we have not been able to expose such things firsthand. I have a suspicion that he may be right, that things are moving in that direction, and for the reasons that I stated. First, we are not often called to a home situation, and when we are, we are largely limited to the information that we are given. If it can be demonstrated that someone was terminally ill, and those present appear to be behaving appropriately, it is difficult to do anything about it. In most cases, suspicions are aroused either because someone says or reports something that

**Le sénateur Corbin:** Pour ce qui est de la participation privée à ces types de recherche, les résultats sont-ils habituellement mis à la disposition de la profession en général ou est-ce limité, confidentiel, du fait des droits de propriété, de la mise au point de certains médicaments, et cetera? Où en est-on à ce sujet?

**Dr Friesen:** Toutes les connaissances émanant des investissements en recherche que font les gouvernements fédéral et provinciaux et les organismes à but non lucratif sont publiques. Je suppose que les connaissances qui émanent des recherches financées par le secteur privé aboutissent de façon générale aussi dans le domaine public plus rapidement que par le passé. Surtout s'il y a un partenariat avec le gouvernement fédéral comme dans le cas du Conseil de recherches médicales. Tous ces sujets de recherche sont publiés. Les listes sont disponibles.

Ce n'est pas tellement une question de domaine public ou privé, mais plutôt de dissémination et d'utilisation de ces nouvelles connaissances. Il y en a de plus en plus, cela change de plus en plus vite, si bien que même un médecin qui essaie de se tenir à jour a du mal à absorber tous les nouveaux renseignements qui pourraient être utiles.

Une nouvelle tendance est que des patients ou clients qui sont mieux renseignés arrivent armés d'informations glanées sur Internet. Cela permet un dialogue mieux éclairé entre le patient ou le client et le praticien. Le client déclare: «Docteur, j'ai lu toutes ces informations. Pourquoi n'utilisons-nous pas plutôt ce médicament que celui-ci?» C'est un nouvel aspect intéressant de la pratique médicale, c'est à mon avis probablement assez sain.

**Le sénateur Corbin:** Docteur Young, pour poursuivre l'échange que vous aviez avec le sénateur Beaudoin sur la clarification de certaines choses dans le Code criminel, je suppose que vous ne défendiez pas le meurtre pour raison de compassion?

**Dr Young:** Non. Je ne dis pas qu'il faudrait nécessairement changer quoi que ce soit dans la définition. Je dis que quelle que soit la définition que l'on utilise — et à supposer que nous nous en tenions à la définition actuelle —, il devrait être indiqué clairement dans la loi, il devrait y avoir une infraction précise dans le Code criminel disant que: «Si l'on va plus loin, c'est l'euthanasie et voici les peines prévues pour cela».

**Le sénateur Corbin:** Docteur Young, j'aimerais avoir vos réactions aux observations de M. Ogden sur les services clandestins, organisés, d'aide à la mort. Cela vous pose-t-il un problème?

**Dr Young:** Cela pose un gros problème. Je sais qu'il y eu des rapports à ce sujet. En Ontario, nous n'avons pu exposer directement ce genre de choses. Je ne serais pas étonné qu'il ait raison, que les choses évoluent dans ce sens et pour les raisons que j'ai indiquées. Tout d'abord, nous ne sommes pas souvent appelés à domicile et, quand nous le sommes, nous devons en général nous contenter des informations qui nous sont données. Si l'on peut prouver que quelqu'un était en phase terminale et que ceux qui sont présents semblent se comporter normalement, il est difficile de faire quoi que ce soit. Dans la plupart des cas, si l'on a



launches an investigation or, in the case of hospitals, because there is an unexpected element to a death.

**Senator Roche:** Once again, I am driven back to one of my principal concerns. It seems to be almost impossible to draw a sharp dividing line between palliative care, which we support, and moving toward euthanasia. The testimony this morning has been quite remarkable in that respect. I took from Dr. Young's comment that under an umbrella of palliative care, and often in individual homes, there are some suspicious cases. I will leave that comment for now and invite Dr. Young to make any additional response that he wishes.

Mr. Ogden has given us what I would almost call "bombshell" testimony. Although I thought I was following this field of study fairly closely, I did not know that there was an underground assisted death movement, which he is calling "deathing counter-culture". He says that it is an organized, underground movement that is virtually unstoppable and appears to be a growth industry.

I suggest that we take this testimony very seriously, if it is credible — and I am not suggesting that Mr. Ogden's testimony is not credible — or we dismiss it. It is tantalizing, but there is insufficient empirical evidence that this deliberate development of a death industry is taking place. I am left with the same confusion that I have expressed before: How can we discuss palliative care and the need to strengthen all the bases for it without also addressing Dr. Young's testimony — and I will invite him to respond first — about there being a line that people must understand they cannot cross?

**Dr. Young:** There are a number of public organizations dedicated to ensuring that people are comfortable and can die with dignity. I am not using the name of any one in particular. There are also groups such as the Hemlock Society, but whether or not those groups represent what Mr. Ogden was talking about, I honestly do not know. I do not know the extent of their activities because they are very difficult to investigate. The book published by the Hemlock Society, which indicates how to induce death chemically, has created major problems for coroners and medical examiners across North America. In many instances, it became a primer for people who were not terminally ill, but who rather were depressed and wanted to commit suicide. If these mechanisms exist — and I do not know that they do — could they and would they be misused? My suspicion is they would be. The book was used and misused. The underground movement involved in that book grew. Beyond that, I would have to defer to Mr. Ogden. I am in the unenviable position of wondering if it indeed exists and I cannot find it.

**Senator Roche:** Before we go to Mr. Ogden, Dr. Young, morally acceptable and legally permissible palliative care includes, among other things, the withdrawal of treatment and the administration of morphine in very large doses. Is it your professional opinion that these two instruments are employed deliberately to hasten death in some of cases to which you have referred?

des doutes, c'est parce que quelqu'un dit ou rapporte quelque chose qui enclenche une enquête, ou, dans le cas des hôpitaux, parce qu'il y a un élément inattendu dans un décès.

**Le sénateur Roche:** Je reviens encore une fois à l'une de mes principales préoccupations. Il semble presque impossible de faire une distinction nette entre les soins palliatifs, que nous favorisons, et la tendance vers l'euthanasie. Le témoignage que nous avons eu ce matin est tout à fait remarquable à cet égard. Je conclus des observations du Dr Young que dans le cadre général des soins palliatifs, et souvent à domicile, il y a certains cas assez douteux. J'en resterai là pour le moment et inviterai le Dr Young à ajouter quelque chose s'il le souhaite.

M. Ogden nous a présenté un témoignage que je qualifierais presque de «coup de théâtre». Alors que je pensais que je suivais ce domaine d'assez près, je ne savais pas qu'il y avait un mouvement clandestin d'aide à la mort qu'il appelle la «contre-culture de la mort». Il dit que c'est un mouvement organisé et clandestin qu'il est pratiquement impossible d'arrêter et qui semble se développer.

Je suggérerais que nous prenions ce témoignage très au sérieux, si c'est crédible — je ne veux pas dire que le témoignage de M. Ogden ne soit pas crédible — ou que nous le rejetions. En tout cas, il ne semble pas qu'il y ait suffisamment de preuves empiriques que cette nouvelle industrie se développe. Je reste devant le même dilemme que tout à l'heure: comment peut-on discuter de soins palliatifs et de la nécessité de les renforcer à tous points de vue sans tenir compte du témoignage du Dr Young — sur la limite qu'il faut que les gens comprennent qu'ils ne peuvent franchir?

**Dr Young:** Il y a un certain nombre d'organisations publiques qui s'efforcent de veiller à ce que les gens puissent mourir dans la dignité. Je ne les nommerai pas. Il y a aussi des groupes comme la Hemlock Society, mais je ne sais vraiment pas si ces groupes représentent ce dont parlait M. Ogden. Je ne sais pas jusqu'où vont leurs activités parce qu'il est très difficile de faire enquête à leur sujet. Le livre publié par la Hemlock Society, qui indique comment provoquer la mort par des moyens chimiques, a créé de gros problèmes pour les médecins légistes et les médecins examinateurs en Amérique du Nord. Dans bien des cas, c'est devenu un outil pour des gens qui n'étaient pas en phase terminale mais qui étaient déprimés ou voulaient se suicider. Si de tels mécanismes existent — et je ne le sais pas —, pourraient-ils et seraient-ils utilisés à mauvais escient? Je le crois. Ce livre a été utilisé et pas toujours à bon escient. Le mouvement clandestin qui est à l'origine de ce livre s'est développé. Pour le reste, je devrais laisser M. Ogden répondre. Je me trouve dans la position peu agréable de me demander si cela existe effectivement et de ne pouvoir le prouver.

**Le sénateur Roche:** Avant que nous ne passions à M. Ogden, docteur Young, les soins palliatifs moralement acceptables et légalement autorisés incluent, entre autres, l'interruption d'un traitement et l'administration de morphine à fortes doses. Êtes-vous professionnellement d'avis que ces deux instruments sont employés délibérément pour hâter la mort dans certains des cas auxquels vous avez fait allusion.

**Dr. Young:** I am not sure whether I would include withdrawal, although it could hasten death. The fact is that it is the person's right to refuse the treatment. I would be inclined to say that falls within an acceptable range. Are medications used to hasten death? It is my belief that this does happen on occasion.

**Senator Roche:** Therefore, as this committee discusses the enhancement of good palliative care, we would have to point out that this overuse of drugs is not acceptable?

**Dr. Young:** That is important. Clarity in drawing a line is very important. With the promotion of good palliative care, the chances of people then wishing to intentionally cross that line diminish. That is why I support Dr. MacDonald's views so strongly. They are one more step, along with the clarity, in ensuring that people stay on the right side of that important line.

**Senator Roche:** That point has been made frequently in the testimony and has been helpful.

**Mr. Ogden:** I start with your last sentence: I raised this business about the underground movement "because we need to consider the consequences of choosing prohibition of assisted suicide and voluntary euthanasia rather than other forms of regulation and social control."

With great respect, I do not know what you are talking about in that sentence.

**Mr. Ogden:** When I referred to the consequence of choosing prohibition, I meant that it forces people to pursue alternatives that they cannot achieve through the legal system.

For example, if an individual cannot access a legal assisted death, and is convinced that euthanasia is desirable, he or she will find the means. In this case, the means involve a number of devices that I have alluded to here. One of them is known as a "de-breather", which literally recycles one's own air until oxygen is depleted and the body dies. Others devices involve the breathing of inert gases, such as helium and nitrogen. Death from breathing these gases, which are readily available in our own atmosphere, occurs within a matter of minutes. Some reports state as quickly as six or seven minutes.

The point I am trying to make is that when we prohibit certain behaviours, and members of the public still desire to engage in those behaviours, they will find other ways of doing so. Prohibition of alcohol leads people to construct their own distilleries. Prohibition of prostitution means that people will still find other, illegal ways of engaging in it. Prohibition of legal assisted death means that some individuals will still find ways to access this kind of service.

The benefit of supporting regulation and other forms of social control is that, if we are open to the legalization or quasi-legalization of certain behaviours, we can bring them under some form, not only of state observation, but also professional and societal observation.

**Dr. Young:** Je ne sais pas si j'inclurais l'interruption, mais en fait cela pourrait accélérer la mort. Le fait est qu'une personne a le droit de refuser un traitement. Je serais porté à dire que cela est acceptable. Des médicaments sont-ils utilisés pour accélérer la mort? À mon avis cela se produit à l'occasion.

**Le sénateur Roche:** Ainsi, dans le cadre de l'étude par notre comité de l'amélioration des soins palliatifs, il nous faudrait signaler que cette surutilisation des médicaments n'est pas acceptable?

**Dr. Young:** C'est important. Il faut dire clairement jusqu'où on peut aller. Si l'on fait la promotion de bons soins palliatifs, il y a moins de chance que les gens dépassent volontairement les limites. C'est pourquoi je suis tant en faveur des propositions du Dr MacDonald. Assorties des précisions nécessaires dans la loi, elles aideront à faire en sorte que les gens respectent ces limites importantes.

**Le sénateur Roche:** Plusieurs témoins ont fait ce commentaire, et cela nous a été fort utile.

Monsieur Ogden, j'aimerais revenir à votre dernière phrase: Si je mentionne ce mouvement clandestin, «c'est qu'il faut tenir compte des conséquences du choix de l'interdiction de l'aide au suicide et de l'euthanasie volontaire plutôt que d'autres options comme la réglementation et le contrôle social.»

Je dois avouer que je ne sais vraiment pas ce à quoi vous voulez en venir.

**M. Ogden:** Lorsque j'ai parlé des conséquences du choix de l'interdiction, je voulais dire que cela force automatiquement les gens à chercher d'autres solutions qu'ils ne peuvent trouver dans le système juridique.

Par exemple, si un particulier ne peut pas avoir accès de façon légale à l'aide à la mort, et est convaincu que l'euthanasie est la seule solution, il trouvera les moyens. Dans le cas qui nous occupe, cela veut dire qu'on aura recours aux mécanismes dont j'ai parlé. Je pense par exemple à celui qu'on appelle le «dérespirateur», qui recycle en fait l'air respiré par une personne jusqu'à ce qu'il y ait mort par asphyxie. D'autres dispositifs permettent la respiration de gaz inertes, comme l'hélium et l'azote. Ceux qui respirent ces gaz, qui existent en fait dans notre atmosphère, meurent dans quelques minutes. D'après certains rapports, ils meurent en cinq ou six minutes.

Ce que j'essaie de dire c'est que lorsque nous interdisons certains comportements, et que certains citoyens veulent toujours faire ces choses interdites, ils trouveront d'autres façons de le faire. L'interdiction de l'alcool a mené les gens à construire leurs propres distilleries. L'interdiction de la prostitution veut simplement dire que les gens trouvent d'autres façons de se livrer à ce genre d'activités illégales. L'interdiction de l'aide légale au suicide veut simplement dire que certains particuliers trouveront des façons d'avoir accès à ce genre de service.

Par contre, l'avantage des règlements et des autres formes de contrôle social, lorsque l'on est réceptif à la légalisation ou la quasi-légalisation de certains comportements, c'est que cela nous permet d'assurer une certaine forme de surveillance sociétale, professionnelle et gouvernementale.



I know that this committee is not comfortable with importing the Dutch experience into Canada, but one of the outcomes of regulating euthanasia in the Netherlands is that assisted suicide in that country is actually a very socially controlled behaviour. Over the last 20 years, access to euthanasia and assisted suicide has become increasingly regulated in Holland. There are currently far more social controls over those behaviours than previously.

**Senator Roche:** Are you an advocate of the Dutch experience?

**Mr. Ogden:** I would say that there are benefits to the Dutch experience, but I do not know whether it is exportable to Canada. I think that we must solve these problems here.

**Senator Roche:** I took it from your testimony about this underground movement that someone — whether it is us or some element of the law — should do something about it. Your testimony leaves me in some confusion; it may be my own inadequacies.

I do not know what to do about this testimony, Madam Chair. I do not know whether to take seriously that there is an underground movement and pursue it to see if there are more facts, and invite the witness to give us more detailed information, or dismiss it.

**The Chairman:** To pursue it at this point, quite frankly, would not be relevant to our study. However, what is relevant is that we did make a recommendation that research should be conducted in this country to find out why people want to access euthanasia and assisted suicide. That was one of our unanimous recommendations.

What is relevant from what Professor Ogden has said today is that that research has not been conducted. In fact, if I understand correctly from Mr. Ogden's presentation, not only has it not been conducted, but also, at least specifically in your case, obstacles have been put in your way. Is that essentially what you wanted to contribute today?

**Mr. Ogden:** Yes.

**Senator Roche:** If there is an underground movement — a growth industry, as Professor Ogden says — that promotes death, do you not think the public and the Parliament of Canada should know about it? We should understand its full dimensions before we attempt a report that will deal with this whole area.

**The Chairman:** Except that we would then be going into non-unanimous recommendations of this committee. If you give careful reading to what we wrote in our first report, you will note that we knew then of evidence that euthanasia and assisted suicide, for a variety of reasons and by various means, was going on in Canada.

**Senator Roche:** However, he called it a growth industry.

Je sais que l'idée d'importer l'expérience hollandaise au Canada ne sourit guère à votre comité, mais la réglementation de l'euthanasie dans ce pays a eu pour effet de rendre cette activité un comportement très contrôlé par la société. Au cours des 20 dernières années, l'accès à l'euthanasie et à l'aide au suicide est devenu de plus en plus réglementé en Hollande. Il existe en fait actuellement beaucoup plus de contrôle social sur ce genre de comportements qu'auparavant.

**Le sénateur Roche:** Êtes-vous un défenseur de l'expérience hollandaise?

**M. Ogden:** Je dirais simplement que cette expérience présente des avantages, mais je ne sais pas s'il serait possible de l'exporter au Canada. Je crois que nous devons régler nos problèmes ici.

**Le sénateur Roche:** D'après votre témoignage j'en conclus que quelqu'un — soit nous ou le système juridique — doit faire quelque chose pour régler le problème que présente ce mouvement clandestin. Vos commentaires me laissent un peu perplexe; c'est peut-être simplement que je n'arrive pas à comprendre.

Je ne sais pas à quoi m'en tenir dans le cas de ce témoignage, madame la présidente. Je ne sais pas si je dois prendre cela au sérieux, la présence d'un tel mouvement clandestin, et essayer d'obtenir plus de renseignements, demander au témoin de nous en dire un peu plus long, ou simplement ne pas en tenir compte.

**La présidente:** Pour être honnête, il ne serait pas du tout utile dans le cadre de notre étude de nous pencher plus à fond sur cette question. Cependant, il faut se rappeler que nous avons formulé une recommandation proposant que des recherches soient effectuées au Canada afin de découvrir pourquoi les gens veulent avoir accès à l'euthanasie et à l'aide au suicide. C'était là une des recommandations que nous avons adoptées à l'unanimité.

Ce qui est pertinent dans ce que M. Ogden nous a dit aujourd'hui, c'est qu'en fait cette recherche n'a pas été effectuée. Enfin, si j'ai bien compris ce qu'a dit M. Ogden, non seulement cette recherche n'a pas été effectuée, mais de plus, du moins dans le cas de M. Ogden, on a posé des obstacles à cette recherche. Est-ce que vous voulez nous dire aujourd'hui?

**M. Ogden:** Oui.

**Le sénateur Roche:** S'il y a un mouvement clandestin — une industrie en pleine croissance selon la description de M. Ogden — qui fait la promotion de la mort, ne croyez-vous pas que le public et le Parlement devraient être mis au fait de la situation? Nous devrions en connaître tous les aspects avant de préparer un rapport qui portera sur la question.

**La présidente:** Le problème c'est que si nous faisons cela, nous passerions à des recommandations non unanimes du comité. Si vous lisez attentivement notre premier rapport, vous noterez que nous savions alors que l'euthanasie et l'aide au suicide, pour diverses raisons et par divers moyens, étaient des choses qui existaient au Canada.

**Le sénateur Roche:** Cependant, notre témoin a parlé d'une industrie en pleine croissance.



**The Chairman:** Whether it is a growth industry, whether or not it has grown since 1995, we do not know, since we decided deliberately not to look at euthanasia and assisted suicide.

It is also fair to say that we did hear evidence, and not just from Mr. Ogden, that people were committing euthanasia themselves. They were getting assistance in euthanasia from others, even in 1995. I do not think that it is in this committee's interest at this time to go down that particular road.

I have a question for Professor Mishara, who thus far has been left out of all this.

I read with great interest your Omega article, particularly the detailed research you did to make the connection, as has Dr. Harvey Chochinov, between dying and depression. However, the fundamental question is, can you force treatment for depression on people? You cannot force any other treatment on them.

**Mr. Mishara:** I do not think that is the main issue. It is a question of recognizing that depression may be present. This is the problem with technical solutions such as legislation, which inhibits certain behaviours and permits others.

For example, right now people very clearly have the right to refuse or stop treatment. That is a technical solution, but we know that many people who decide to stop treatment are clinically depressed. No one has said, "Maybe that person is clinically depressed. Maybe that person should be offered some treatment or help, or counselled about this." The only legal solution we have is a technical one; that is, "This is a right. I say, stop treatment". The issue becomes not what is inhibited or permitted, legal or illegal, but the obligations of a society to understand the complex dynamics involved in life/death situations and to provide services.

Obviously, there is not much one can do if someone says, "No, I do not want to take any antidepressants. I do not want to talk to anyone about it. I just want the machine unplugged." You have a very clear right to refuse treatment. That is something that is unchangeable.

However, in research and in proposing solutions, it is easier to decide that we will spend our money on pain medication. There is a lot of research going on, but it is mostly in the area of pain control, while other, psychological dimensions are ignored. Dr. MacDonald proposed some criteria for good palliative care that go far beyond simply controlling pain. This is relevant to issues like the underground death movement. If people are, for whatever motivations, seeking out a premature death, there will be means of finding it. No one who engages in the compassionate murder of a loved one is really thinking, at the moment, "This is illegal. I might go to jail for it." They are thinking, "Someone I love is suffering. I have to do this."

**La présidente:** Qu'il s'agisse d'une industrie en pleine croissance ou pas, que le problème soit plus marqué qu'en 1995 ou pas, nous ne le savons pas puisque nous avons décidé délibérément de ne pas étudier l'euthanasie et l'aide au suicide.

Je crois qu'il est juste de dire que nous avons entendu d'autres témoignages, en plus de celui de M. Ogden, qui indiquaient qu'il y avait des gens qui pratiquaient l'euthanasie. Ils obtenaient de l'aide pour l'euthanasie, déjà en 1995. Je ne crois pas qu'il est dans l'intérêt du comité d'étudier plus à fond, pour l'instant, cet aspect.

J'aimerais poser une question à M. Mishara, qui n'a pas encore participé à la discussion.

J'ai lu avec beaucoup d'intérêt votre article dans Omega, tout particulièrement en ce qui a trait à la recherche détaillée que vous avez faite afin d'établir le lien, comme l'a fait M. Harvey Chochinov, entre la mort et la dépression. Cependant, il reste une question fondamentale: Peut-on imposer un traitement pour la dépression à des patients? Vous ne pouvez pas imposer d'autres types de traitement aux patients.

**M. Mishara:** Ce n'est pas là à mon avis que se situe le vrai problème. Il s'agit plutôt de reconnaître que c'est peut-être un cas de dépression. Voilà la difficulté que présentent les solutions techniques comme une mesure législative, qui interdit certains comportements et en autorise d'autres.

Par exemple, actuellement les gens ont clairement le droit de refuser ou d'arrêter un traitement. C'est une solution technique, mais nous savons que beaucoup de gens qui décident de mettre fin à un traitement souffrent de dépression clinique. Personne n'a dit: «Peut-être ce patient souffre-t-il de dépression clinique. Peut-être devrions-nous lui offrir un traitement ou une aide ou du counselling.» La seule solution légale qui s'offre à nous est une solution technique, c'est-à-dire: «C'est un droit, je veux arrêter le traitement.» La question n'est plus de se demander ce qui est autorisé ou interdit, légal ou illégal, mais plutôt de reconnaître l'obligation d'une société de comprendre les dynamiques complexes qui caractérisent les situations de vie et de mort ainsi que l'obligation d'assurer les services nécessaires.

Évidemment, on ne peut pas faire grand-chose si quelqu'un dit: «Non, je ne veux pas prendre d'antidépresseur. Je ne veux parler à personne de ma situation. Je veux simplement qu'on débranche.» On a clairement le droit de refuser un traitement. Ça c'est incontournable.

Cependant, dans la recherche et en proposant des solutions, il est plus facile de décider que nous dépenserons notre argent pour des analgésiques. D'importantes recherches se déroulent actuellement, mais elles portent plutôt sur le contrôle de la douleur, alors que les autres aspects, les dimensions psychologiques, sont oubliés. M. MacDonald a proposé certains critères pour de bons soins palliatifs qui ne se limitent pas au contrôle de la douleur. Cela est pertinent quand on parle de questions comme le mouvement clandestin pour l'aide à la mort. Si les gens, peu importe la raison, cherchent à mourir prématurément, ils trouveront un moyen d'atteindre leur objectif. Ceux qui participent au meurtre par compassion pour un être cher ne se disent pas

The problem is that the technical solutions are not necessarily adequate. This whole process of education and awareness and providing information is much more difficult to ensure. From my point of view, it is much more important than making something now legal illegal, or proposing very technical solutions.

**The Chairman:** The fifth core principle of the document presented by Dr. MacDonald refers to assessing and managing various problems, and I think the order given is important. It references psychological, social, spiritual, and religious problems. You see an assessment of and treatment for depression as part of quality end-of-life care, if it is desired by the patient and perhaps the patient's family?

**Mr. Mishara:** Yes. There are clear indications that this is not often available. Currently, when it is available in Canada, it is for a certain elite who suffer from cancer, who have refused further medical interventions, and who have managed to live in a large city where good palliative care service is available.

**Senator Beaudoin:** Dr. Mishara, at the end of your presentation, you state, "Research indicates that family members often knowingly do not respect the patient's expressed desire. Some studies show that family members tend to rely solely upon recommendations of physicians..." You conclude from that that "Physicians and other caregivers often feel ill at ease and lack clear guidance concerning how to react to family members..."

We need guidelines, but the situation may vary from one province to another. Some provinces already have legislation to which the doctors are obliged to give effect. For example, we are improving more and more the area of living wills, of writing down the mandate and the "procurator", as we say in French. These documents are legal and binding on doctors and caregivers.

What do you suggest on the development of guidelines? For me, it may be partly a question of law, but perhaps you have something else in mind.

**Mr. Mishara:** In some cases there is a written, signed document, but often there is not because people do not anticipate that their situation will worsen, that they will become comatose or unable to make decisions for themselves.

There are studies available from other countries, and I have no reason to believe that Canadian results would be any different. For example, in Israel a lengthy investigation of just who is making the decisions was undertaken. Very often, when a person is incapacitated, the family is consulted. "What do we do? Do we unplug the machine?" This is a very difficult situation. The

lorsqu'ils posent le geste: «Cela est illégal. J'irai peut-être en prison.» Ils se disent: «Quelqu'un que j'aime souffre, je dois agir.»

Le problème, c'est que les solutions techniques ne sont pas nécessairement adéquates. Ce processus d'éducation et de sensibilisation, de communication des renseignements, est beaucoup plus difficile à garantir. Personnellement, je crois que cela est beaucoup plus important que simplement s'assurer que quelque chose qui est actuellement légal devient illégal ou de proposer des solutions très techniques.

**La présidente:** Le cinquième élément clé du document présenté par M. MacDonald porte sur l'évaluation et la gestion de divers problèmes; je crois que l'ordre dans lequel les choses sont présentées est très important. On y parle de problèmes psychologiques, sociaux, spirituels et religieux. Jugez-vous que l'évaluation et le traitement de la dépression fait partie de soins de qualité à la fin de la vie, si c'est ce que désire le patient, ou peut-être sa famille?

**M. Mishara:** Oui. Tout semble indiquer que ce genre de service n'est pas souvent disponible. Actuellement, lorsqu'il est disponible au Canada, c'est pour une certaine élite qui souffre de cancer, qui a déjà refusé d'autres interventions médicales, et qui vit dans une grande ville où de bons soins palliatifs sont disponibles.

**Le sénateur Beaudoin:** Monsieur Mishara, à la fin de votre exposé, vous dites «Les travaux de recherche révèlent que les membres de la famille ne respectent pas, souvent sciemment, les désirs exprimés par le patient. Certaines révèlent que les membres de la famille ont tendance à se fier exclusivement aux recommandations présentées par les médecins...» Vous concluez ainsi que «les médecins et les autres fournisseurs de soins se sentent souvent mal à l'aise et n'ont pas de lignes directrices claires quant à la façon de réagir face aux demandes des membres de la famille...»

Nous avons besoin de lignes directrices, mais la situation peut varier d'une province à l'autre. Certaines provinces ont déjà des lois qui stipulent que les médecins doivent agir. Par exemple, nous améliorons de plus en plus toute la question entourant les testaments de vie, le fait de coucher sur papier le mandat et la procurator. Ces documents sont des documents juridiques et exécutoires et doivent donc être respectés par les médecins et les fournisseurs de soins.

Pouvez-vous faire des suggestions à l'égard de lignes directrices? Personnellement, je pense que c'est peut-être en partie une question juridique. Peut-être avez-vous une autre idée.

**M. Mishara:** Dans certains cas il existe un document signé mais souvent ces documents n'existent pas parce que les gens ne s'attendent pas à ce que leur situation empire, ne s'attendent pas à tomber dans le coma ou à ne pas être en mesure de prendre eux-mêmes les décisions qui les touchent.

Des études ont été effectuées dans d'autres pays, et je n'ai aucune raison de croire que les résultats au Canada seraient différents. Par exemple, en Israël, une longue enquête a été effectuée afin de déterminer qui prenait les décisions. Très souvent, lorsqu'une personne est incapable de prendre des décisions, on consulte sa famille. «Que faisons-nous? Débran-



research suggests that family members will often make a decision that is more consistent with what they think is best for the person, regardless of what he or she has said earlier. A person may have said, "I want to be unplugged. I do not want to continue living," but a loving family member will not have the heart to do it.

The studies report that when family members are asked how they came to their decisions, they often respond that they asked the doctor what to do.

Again, we go to back to Dr. MacDonald's testimony. There is very little training in medical schools about how to respond when a family member asks a doctor what to do. This is rarely part of a doctor's formal medical training, and even if it is, we do not have guidelines that state under what circumstances to give what form of advice. The doctors often feel very ill at ease.

That result has been expressed in surveys in Ontario, for example, of physicians regarding requests for euthanasia by family members and individuals. They want to know how to answer when someone says, "What do I do?" There needs to be some sort of formal consensus that is included in the training.

I also touched on the issue of informed consent. All research to date suggests that what people say they would like in the future is not necessarily related to what they actually want, if they are conscious and capable of expressing that desire, later on. This poses ethical issues and practical concerns because there is an incredible inconsistency. It is very easy when you are in good health and not dying to say, "If I was ever hooked up to a machine that was keeping me alive, I would like to have it unplugged." However, when you are actually hooked up to that machine and facing death, very often you do not feel the same way about things. There are moral, legal, and technical issues with advance directives.

Technical solutions are often not adequate. We can pass a law saying that people must write out their wishes and others must respect them, making everything clear, or we can regulate additional pain medication, but what we really want is to humanize care, and that is something that cannot be legislated. Policies and practices must be developed and then made available.

**Senator Beaudoin:** If someone states in his will that he wishes not to be resuscitated in a certain situation, and if the family asks the doctor to ignore that will, the doctor would be taking a chance, because a will is a will.

chons-nous cet appareil?» C'est une situation très difficile. Ces études révèlent que les membres de la famille prendront souvent la décision qui correspond le mieux avec ce qu'ils jugent être à l'avantage du patient, peu importe ce que ce patient avait dit plus tôt. Quelqu'un aurait peut-être dit: «Je veux qu'on débranche. Je ne veux pas continuer à vivre.» Mais un être cher n'aura pas le cœur de le faire.

Ces études révèlent que lorsqu'on demande aux membres de la famille comment ils en sont venus à une décision, ils répondent souvent qu'ils avaient demandé au médecin.

Encore une fois, nous revenons à ce qu'a dit M. MacDonald. Très peu de formation est offerte dans les facultés de médecine pour enseigner aux futurs médecins comment répondre quand un membre de la famille demande au médecin quoi faire. Cela fait rarement partie de la formation médicale officielle d'un médecin, et même quand ces cours existent, il n'existe pas de lignes directrices qui indiquent dans quelles circonstances on doit offrir certains types de conseils. Les médecins se sentent souvent très mal à l'aise.

Enfin, c'est ce qu'ont dit certains médecins qui ont été consultés lors d'un sondage effectué en Ontario pour connaître leurs réactions face aux demandes d'euthanasie par des particuliers ou des membres de famille. Ils veulent savoir comment répondre quand quelqu'un demande: «Que dois-je faire?». Il doit y avoir une forme de consensus officiel qui serait inclus dans la formation du médecin.

J'ai également abordé la question du consentement éclairé. Tous les travaux de recherche effectués indiquent que ce que les gens disent qu'ils voudraient à l'avenir n'est pas nécessairement lié à ce qu'ils veulent vraiment, lorsqu'ils sont conscients et capables d'exprimer leurs désirs. Cela pose un problème déontologique et pratique parce qu'il y a vraiment une différence marquée. C'est très facile lorsque vous êtes en bonne santé et que vous ne mourrez pas de dire: «Si jamais je suis branché et que c'est l'appareil qui me permet de vivre, je veux qu'on me débranche.» Cependant, lorsque dans les faits vous êtes branché à cet appareil et que la mort vous attend, vous n'avez pas nécessairement la même opinion. Les directives préalables posent donc certains problèmes moraux, juridiques et techniques.

Très souvent les solutions techniques ne sont pas adéquates. Nous pouvons adopter une loi stipulant que les gens doivent coucher par écrit leurs désirs et que les autres sont tenus de les respecter, tout indiquer clairement, ou nous pouvons adopter des règlements régissant les prescriptions en plus grande quantité d'analgésiques, mais ce que nous voulons faire, c'est rendre les soins humains, et c'est quelque chose qu'on ne peut pas légiférer. Les politiques et les pratiques doivent être élaborées puis mises en oeuvre.

**Le sénateur Beaudoin:** Si quelqu'un stipule dans son testament qu'il ne veut pas être réanimé dans certaines circonstances, et si la famille demande à ce médecin de ne pas tenir compte du testament, le médecin prendrait des risques importants parce qu'un testament c'est un testament.



**Mr. Mishara:** A will is a will but, in practice, the doctor may ask the family if there is one, and family members can answer any way they want. The will is not automatically transferred to the doctor.

**Senator Beaudoin:** In some provinces, it is registered and we the jurists try to refine the system. Of course, the will states something, but it must be read.

**Mr. Mishara:** In an instance of clear directives, the doctor must follow them. However, in many circumstances, there is no will and no indication, but for a family conversation or discussion at some point in time.

The studies I mentioned, where family members do not necessarily respect their wishes, reflect those instances where they report what the person said they wanted, but subsequently make another decision on advice from the doctor. I do not know what percentage of Canadians have living wills of some sort. The other issue is that people are fickle in terms of what they thought they would want 10 years before when they made out their living wills.

**Senator Beaudoin:** It is law in the making, as we say.

**Senator Corbin:** My question is to Dr. Young, and perhaps Professor Mishara may wish to respond too, because being the serious person he is, Dr. Mishara would weigh his words carefully. He relates survey studies and talks about research.

Dr. Young, you said that surveys are flawed from the beginning. You even went so far as to qualify the word "flawed", but I forget how.

**Dr. Young:** Yes.

**Senator Corbin:** One objective of this committee is to ensure that we do come up with precise, non-controversial definitions that everyone plainly understands, whether in the field of medical practice, or criminal law, or just John Q. Public. Why is it that you do not seem to have any faith at all in surveys?

**Dr. Young:** I should qualify that. I accept what I said, and I said it in strong terms. The type of survey to which I referred is the poll that asks, "Are you in favour of euthanasia?"

**Senator Corbin:** Precisely.

**Dr. Young:** The question is vague and can elicit many answers because different people think of it in different terms.

**Senator Beaudoin:** That is right.

**Dr. Young:** Most people would answer "yes" in the case of someone with intractable pain, leaving aside the argument of whether or not it can be treated. If you then ask, "Are you in favour of euthanasia for parents with Alzheimer's disease," fewer people would say "yes". However, the survey question does not ask that and does not make that distinction. In my mind, they are answering the question in terms of whether or not the suffering person deserves euthanasia. However, that could include Alz-

**M. Mishara:** Un testament est un testament mais, en pratique, le médecin peut demander à la famille s'il y a testament et les membres de la famille peuvent répondre ce qu'ils veulent. Le testament n'est pas automatiquement transféré au médecin.

**Le sénateur Beaudoin:** Dans certaines provinces, le testament est enregistré et nous, les juristes, essayons d'améliorer le système. Évidemment, on dit quelque chose dans le testament mais il faut le lire.

**M. Mishara:** Lorsqu'il y a des directives claires, le médecin doit les respecter. Cependant, dans nombre de cas, il n'y a pas de testament et pas de directive; à ce moment-là tout ce qu'on sait c'est ce qui a été dit lorsque la famille avait abordé la question.

Les études que j'ai mentionnées font état du fait que dans certains cas les membres de la famille ont avoué qu'ils ne respectaient pas nécessairement les désirs de leur être cher et que même s'ils savaient ce que le patient aurait voulu ils ont pris une autre décision après avoir obtenu les conseils du médecin. Je ne sais pas quel pourcentage des Canadiens ont préparé un testament de vie. De plus, les gens changent d'idée, alors ce qu'ils pensaient qu'ils auraient voulu il y a dix ans lorsqu'ils ont préparé leurs testaments biologiques a peut être changé depuis.

**Le sénateur Beaudoin:** Cela évolue.

**Le sénateur Corbin:** Ma question s'adresse à M. Young, et peut-être M. Mishara voudra-t-il y répondre aussi, car comme il est si sérieux, M. Mishara va bien peser ses mots. Il parle de résultats de sondage et de recherche.

Monsieur Young, vous avez dit que d'entrée de jeu les sondages ne sont pas fiables. Vous avez même précisé ce que vous entendiez par là mais j'ai oublié ce que vous avez dit.

**Dr Young:** C'est exact.

**Le sénateur Corbin:** Un des objectifs de notre comité est d'assurer que nous trouverons des définitions précises qui ne susciteront pas de controverse et que tout le monde pourra comprendre, qu'il s'agisse de juristes, de médecins ou de Monsieur Tout-le-Monde. Pourquoi semblez-vous n'accorder aucune confiance aux sondages?

**Dr Young:** Je crois que je devrais apporter une précision. Je ne nie pas ce que j'ai dit, et j'ai dit quand même quelque chose d'assez catégorique. Le type de sondage dont je parlais est celui où on demande: «appuyez-vous l'euthanasie?»

**Le sénateur Corbin:** Justement.

**Dr Young:** La question est vague et peut susciter toutes sortes de réponses parce que les gens voient les choses sous un angle différent.

**Le sénateur Beaudoin:** C'est vrai.

**Dr Young:** La majorité des gens répondrait oui si l'on parlait de quelqu'un qui souffre énormément, sans pour autant déterminer si la maladie est incurable ou pas. Si vous demandez: «appuyez-vous le recours à l'euthanasie pour les parents qui souffrent d'Alzheimer», il y a moins de gens qui répondraient oui. Cependant, la question dans le sondage n'est pas posée de cette façon-là et on ne fait pas la distinction. À mon avis, ceux qui répondent aux sondages disent simplement s'ils pensent que la

heimer's patients, persons who are retarded and have serious medical conditions, and people with a terminal disease, if we forget that AIDS is not as terminal as it once was. About 10 years ago, we had cases of attempted suicide in Toronto in which a doctor was convicted. He gave sleeping pills to two patients the day they were diagnosed as being HIV positive. That could fall under the definition of, "Are you in favour of euthanasia?"

My problem is that the question is not specific enough. I have not seen a general survey of Canadians on euthanasia that gives enough detail that I am confident that we are getting the right answer. That is my concern. I hope that clarifies it.

**Senator Corbin:** Perhaps the scholar has some comments.

**Mr. Mishara:** I agree fully with Dr. Young. There are two types of information we can obtain from surveys. One is attitudes and beliefs, and the other is information about behaviour and practices. It is one thing to ask, "Did you do something to have your mother's death occur earlier," or on a survey of physicians, "How many patients have you had who have requested that you do something that ended their life earlier? How many times have you engaged in this behaviour?" Those data give us a good indication of the extent of the practices in the country.

However, on the types of things that Dr. Young mentioned, such as attitudes, "Are you in favour of such and such," you find that people have different understandings of these words. Even if you give the definitions and you get reliable indications of what people believe, this has little relationship to their behaviours. One example is that most Canadians believe that people who suffer from chronic degenerative diseases should have access to euthanasia and would want to end their own lives in those circumstances. In fact, people say, "If I ever had a chronic degenerative disease, I would want to die rather than continue to live." However, the research studies have consistently found that people with a wide range of chronic degenerative diseases are no more suicidal or desirous of dying early than the general population. Some studies have found that they are less suicidal and less desirous of an early death.

Those attitudes must be interpreted with a great deal of caution. However, there are surveys of behaviours and practices that give us valuable information.

**Senator Corbin:** Is it your view that the media treats these surveys with the necessary caution in their presentation to the public?

**Dr. Young:** At the risk of offending the media, I think sometimes they get misreported and we hear that Canadians are in favour of this or against that. I am always very cautious for that very reason. I agree with the professor on the other kind of

personne qui souffre a le droit d'avoir recours à l'euthanasie. Cependant, cela pourrait inclure ceux qui souffrent d'Alzheimer, les déficients mentaux et ceux qui ont de graves problèmes médicaux, comme ceux qui souffrent d'une maladie incurable, même si le sida n'est pas incurable qu'il l'était. Il y a environ dix ans, des gens ont essayé de se suicider à Toronto et un médecin a été trouvé coupable en raison du rôle qu'il avait joué dans cette affaire. Il a donné des somnifères à deux patients le jour où ils ont appris qu'ils étaient séropositifs. Ces patients seraient inclus dans la réponse à la question «Appuyez-vous le recours à l'euthanasie?»

Le problème c'est qu'à mon avis la question n'est pas suffisamment précise. Je n'ai pas encore vue de sondage effectué auprès des Canadiens sur l'euthanasie qui comporte suffisamment de détails pour me convaincre que la bonne réponse a été donnée aux questions. C'est ce qui me préoccupe. J'espère que j'ai bien expliqué ma position.

**Le sénateur Corbin:** Peut-être que le chercheur aurait des commentaires à faire.

**M. Mishara:** Je suis tout à fait d'accord avec M. Young. Il y a deux types d'information qui peuvent ressortir de ces sondages. D'une part, les attitudes et les croyances, d'autre part les comportements et les pratiques. On peut demander d'une part: «Avez-vous fait quelque chose pour avancer le décès de votre mère?», ou, on interroge des médecins: «Comment avez-vous eu de patients qui ont demandé que vous fassiez quelque chose pour mettre plus rapidement fin à leur vie? Combien de fois avez-vous fait quelque chose dans ce sens?» Ces données nous donnent une bonne indication de la fréquence de telles pratiques dans le pays.

Toutefois, pour le genre de choses dont parlait M. Young, telles que les attitudes: «Êtes-vous pour ceci et cela», vous constaterez que les gens comprennent ces mots différemment. Même si vous donnez les définitions et que vous obtenez des indications fiables de ce que croient les gens, cela ne se retrouve pas souvent dans leurs comportements. Un exemple est que la majorité des Canadiens croient que les gens qui souffrent d'affections dégénératives chroniques devraient avoir accès à l'euthanasie et voudraient dans telles circonstances pouvoir mettre fin à leur propre vie. En fait, les gens disent: «S'il m'arrivait d'avoir une affection dégénérative chronique, je préférerais mourir que de continuer à vivre». Toutefois, les études faites à ce sujet ont toujours démontré que les gens qui souffrent de tout un éventail d'affections dégénératives chroniques ne sont pas plus suicidaires ni désireux de mourir rapidement que le reste de la population. On a même constaté qu'ils le sont moins.

Ces attitudes doivent être interprétées avec beaucoup de prudence. Il y a cependant des sondages sur les comportements et les pratiques qui nous donnent des renseignements très précieux.

**Le sénateur Corbin:** Estimez-vous que les médias traitent ces sondages avec les précautions nécessaires dans la façon dont ils les rapportent à la population?

**Dr Young:** Au risque de choquer les médias, je dirais que les reportages sont souvent fautifs et que l'on veut nous faire croire que les Canadiens sont pour ceci ou contre cela. C'est pourquoi je veux toujours me montrer très prudent. Je suis d'accord avec le

questions. I think there is much more reliability to them. Yes, they are misinterpreted, in my view.

**The Chairman:** Thank you very much for your presentation.

I will ask everyone except the senators and the immediate staff to leave now. I wish to go *in camera* for a few minutes.

The committee continued *in camera*.

professeur pour l'autre type de questions. J'estime que ces sondages sont beaucoup plus fiables. Mais, en effet, ils sont mal interprétés.

**La présidente:** Merci beaucoup de votre exposé.

Je vais demander à tout le monde à l'exception des sénateurs et du personnel essentiel de quitter maintenant la salle. J'aimerais que nous siégions à huis clos quelques minutes.

Le comité poursuit ses travaux à huis clos.

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WITNESSES—TÉMOINS

*Dr. Neil MacDonald, Centre for Bioethics, Clinical Research  
Institute of Montreal.*

*Professor Brian Mishara, Department of Psychology, Université  
du Québec à Montréal.*

*From the Office of the Chief Coroner of Ontario:*

*Dr. James G. Young, Chief Coroner.*

*From the Medical Research Council of Canada:*

*Dr. Henry Friesen, President.*

*Mr. Russel Ogden.*

*Dr. Neil MacDonald, Centre de bioéthique, Institut de  
recherches cliniques de Montréal.*

*Professeur Brian Mishara, Département de psychologie,  
Université du Québec à Montréal.*

*Du Bureau du Coroner en chef de l'Ontario:*

*Dr. James G. Young, coroner en chef.*

*Du Conseil de recherches médicales du Canada:*

*Dr. Henry Friesen, président.*

*M. Russel Ogden.*

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Deuxième session de la  
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SENATE OF CANADA

SÉNAT DU CANADA

*Standing Senate Committee on Social Affairs,  
Science and Technology*

*Comité sénatorial permanent des  
affaires sociales, des sciences et de la technologie*

*Proceedings of the Subcommittee to*

*Délibérations du sous-comité de*

## Update “Of Life and Death”

## Mise à jour de «De la vie et de la mort»

*Chair:*  
The Honourable SHARON CARSTAIRS

*Présidente:*  
L'honorable SHARON CARSTAIRS

Tuesday, April 4, 2000

Le mardi 4 avril 2000

Issue No. 9

Fascicule n° 9

### **Ninth meeting on:**

Examination of the developments since the tabling in  
June 1995 of the final report of the Special Senate  
Committee on Euthanasia and Assisted Suicide,  
entitled “Of Life and Death”

### **Neuvième réunion concernant:**

L'étude des faits nouveaux survenus depuis le dépôt,  
en juin 1995, du rapport final du comité sénatorial  
spécial sur l'euthanasie et l'aide au suicide intitulé:  
«De la vie et de la mort»

WITNESSES:  
(See back cover)

TÉMOINS:  
(Voir à l'endos)



THE SUBCOMMITTEE TO UPDATE  
“OF LIFE AND DEATH”

The Honourable Sharon Carstairs, *Chair*

The Honourable Gérard-A. Beaudoin, *Deputy Chair*

and

The Honourable Senators:

\* Boudreau, P.C.  
(or Hays)  
Corbin  
Keon

\* Lynch-Staunton  
(or Kinsella)  
Milne

\* *Ex Officio Members*

(Quorum 3)

*Changes in membership of the committee:*

Pursuant to rule 85(4), membership of the committee was amended as follows:

The name of the Honourable Senator Milne was substituted for that of the Honourable Senator Pépin (*April 3, 2000*).

The name of the Honourable Senator Corbin was substituted for that of the Honourable Senator Kirby (*April 3, 2000*).

The name of the Honourable Senator Kirby was substituted for that of the Honourable Senator Corbin (*March 29, 2000*).

The name of the Honourable Senator Pépin was substituted for that of the Honourable Senator Roche (*March 29, 2000*).

LE SOUS-COMITÉ DE MISE À JOUR DE  
«DE LA VIE ET DE LA MORT»

*Présidente:* L'honorable Sharon Carstairs

*Vice-président:* L'honorable Gérard-A. Beaudoin

et

Les honorables sénateurs:

\* Boudreau, c.p.  
(ou Hays)  
Corbin  
Keon

\* Lynch-Staunton  
(ou Kinsella)  
Milne

\* *Membres d'office*

(Quorum 3)

*Modifications de la composition du comité:*

Conformément à l'article 85(4) du Règlement, la liste des membres du comité est modifiée, ainsi qu'il suit:

Le nom de l'honorable sénateur Milne est substitué à celui de l'honorable sénateur Pépin (*le 3 avril 2000*).

Le nom de l'honorable sénateur Corbin est substitué à celui de l'honorable sénateur Kirby (*le 3 avril 2000*).

Le nom de l'honorable sénateur Kirby est substitué à celui de l'honorable sénateur Corbin (*le 29 mars 2000*).

Le nom de l'honorable sénateur Pépin est substitué à celui de l'honorable sénateur Roche (*le 29 mars 2000*).

**MINUTES OF PROCEEDINGS**

OTTAWA, Tuesday, April 4, 2000

(11)

[English]

The Subcommittee to update "Of Life and Death" met this day in room 257, East Block, at 10:00 a.m., the Honourable Sharon Carstairs, Chair, presiding.

*Members of the subcommittee present:* The Honourable Senators Beaudoin, Carstairs, Corbin and Milne (4).

*In attendance:* Nancy Miller-Chénier, Research Officer, Research Branch, Library of Parliament.

**WITNESSES:**

Virginia (Ginny) Jarvis, Palliative Care Nurse Consultant, Ottawa Hospital.

Dr. David Roy, Clinical Research Institute of Montreal.

Pursuant to its Order of Reference adopted in the Standing Senate Committee on Social Affairs, Science and Technology on Monday, November 29, 1999, the subcommittee continued its examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death". (*For full text of Order of Reference please refer to Issue No. 1.*)

The Chair made an opening statement.

Virginia Jarvis and Dr. David Roy each made statements and answered questions.

At 11:26 a.m., the subcommittee adjourned to the call of the Chair.

ATTEST:

**PROCÈS-VERBAL**

OTTAWA, le mardi 4 avril 2000

(11)

[Traduction]

Le sous-comité de mise à jour de «De la vie et de la mort» se réunit aujourd'hui, à 10 heures, dans la pièce 257 de l'édifice de l'Est, sous la présidence de l'honorable Sharon Carstairs (*présidente*).

*Membres du sous-comité présents:* Les honorables sénateurs Beaudoin, Carstairs, Corbin et Milne (4).

*Également présente:* Nancy Miller-Chénier, attachée de recherche, Direction de la recherche parlementaire, Bibliothèque du Parlement.

**TÉMOINS:**

Virginia (Ginny) Jarvis, infirmière-consultante en soins palliatifs, Hôpital d'Ottawa.

Dr David Roy, Institut de recherches cliniques de Montréal.

Conformément à l'ordre de renvoi adopté par le comité sénatorial permanent des affaires sociales, des sciences et de la technologie, le lundi 29 novembre 1999, le sous-comité poursuit son étude des faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et le suicide assisté intitulé: «De la vie et de la mort». (*Pour le texte intégral de l'ordre de renvoi, voir le fascicule n° 1*)

La présidente fait une déclaration.

Virginia Jarvis et le Dr David Roy font chacun une déclaration et répondent aux questions.

À 11 h 26, le sous-comité suspend ses travaux jusqu'à nouvelle convocation de la présidence.

ATTESTÉ:

*La greffière du sous-comité,*

Heather Lank

*Clerk of the Subcommittee*

## EVIDENCE

OTTAWA, Tuesday, April 4, 2000

The Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 10:00 a.m. to examine the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death."

**Senator Sharon Carstairs** (*Chairman*) in the Chair.

[*English*]

**The Chairman:** Today is our ninth day of hearings under our mandate to update the unanimous recommendations contained in the report of the 1995 Special Senate Committee on Euthanasia and Assisted Suicide, entitled, "Of Life and Death." I would remind honourable senators and witnesses — in particular, those who are watching via the television cameras — that this committee is not reopening the debate on assisted suicide and euthanasia. It is dealing strictly with the areas of the report where the original committee made unanimous recommendations. I would ask everyone to bear this in mind as we proceed through these hearings.

Before us today we have two witnesses, Ms Virginia Jarvis and Dr. David Roy, from the Clinical Research Institute of Montreal. You are both very welcome here this morning. I would ask you to keep your opening statements to 15 minutes, at which point there will be a great number of questions. Please proceed.

**Ms Virginia Jarvis, Clinical Research Institute of Montreal:** Thank you very much for asking me to comment on the current practices concerning pain control and sedation. Before I start, I should like to make my perspective known, and that is of palliative care nursing at a large acute care teaching hospital. I have minimal contact with the community.

In terms of addressing the issues relating to the recommendations made by the Senate committee in 1995, I have not seen a great deal of change in pain control practices.

Overall, there remains a certain amount of ignorance in the treatment of pain, particularly in the terminally ill patient. There also continues to be a fear amongst physicians, nurses, pharmacists, patients and families that opioids cause death, and nothing could be further from the truth. We know that the greatest chance of opioids causing respiratory depression is with the first dose. Further, we are fortunate that, even if this were to occur, there is an antidote to this affect. It is a simple thing to reverse. Moreover, what we know about opioids is that they do not cause any sort of organ damage as do many other medications. Commonly used medications such as non-steroidal, anti-inflammatory drugs can cause irreversible damage to the kidneys and bleeding from the gastrointestinal tract, which can be very life-threatening. Many chemotherapy procedures, for example, can cause any number of life-threatening side effects. By comparison, opioids are much safer drugs.

## TÉMOIGNAGES

OTTAWA, le mardi 4 avril 2000

Le sous-comité de mise à jour de «De la vie et de la mort» du comité sénatorial permanent des affaires sociales, des sciences et de la technologie se réunit aujourd'hui, à 10 heures, en vue d'étudier les faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort».

**Le sénateur Sharon Carstairs** (*présidente*) occupe le fauteuil.

[*Traduction*]

**La présidente:** Aujourd'hui marque le neuvième jour des audiences tenues dans le cadre de notre mandat visant à mettre à jour les recommandations unanimes du rapport du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort». Je vous rappelle, de même qu'aux témoins et à ceux qui suivent nos audiences à la télévision, que le sous-comité ne reprend pas le débat sur l'aide au suicide et l'euthanasie. Il se concentre uniquement sur les parties du rapport où le comité initial avait des recommandations unanimes. Je vous demanderais de ne pas l'oublier.

Nous entendrons aujourd'hui deux témoins, Mme Virginia Jarvis et le Dr David Roy, de l'Institut de recherches cliniques de Montréal. Je vous souhaite à tous deux la bienvenue. Je vous prie de limiter votre déclaration préliminaire à 15 minutes, après quoi nous aurons une foule de questions à vous poser. Nous vous écoutons.

**Mme Virginia Jarvis, Institut de recherches cliniques de Montréal:** Je vous remercie beaucoup de m'avoir invitée à vous parler des pratiques actuelles en matière de maîtrise de la douleur et de sédation. Avant de commencer, je dois vous dire quelle est ma perspective, et c'est celle d'une infirmière spécialisée en soins palliatifs et aigus au service d'un grand hôpital d'enseignement. J'ai fort peu de contact avec le grand public.

Pour ce qui est des recommandations qui ont été faites par le comité sénatorial en 1995, je n'ai pas vu grand changement dans les pratiques relatives à la maîtrise de la douleur.

Il subsiste généralement une certaine ignorance en matière de traitement de la douleur, particulièrement pour ce qui concerne les malades en phase terminale. Parmi les médecins, les infirmiers et infirmières, les pharmaciens, les patients et leurs familles, on continue également de craindre que les opioïdes ne causent la mort, et rien n'est plus faux. On sait que c'est la première dose d'opioïdes qui risque le plus de causer une dépression respiratoire. Même si cela devait se produire, nous avons la chance d'avoir un antidote pour cette condition. Il est aisé d'y remédier. En outre, nous avons la certitude que les opioïdes ne causent aucun tort aux organes, contrairement à bien d'autres médicaments. Les médicaments d'usage courant comme les anti-inflammatoires non stéroïdiens peuvent causer des lésions irréparables aux reins ainsi que des hémorragies dans le tractus gastro-intestinal qui peuvent causer la mort. Nombre d'actes chimiothérapeutiques, par exemple, peuvent avoir des effets secondaires parfois mortels. En comparaison, les opioïdes présentent beaucoup moins de danger.



Physicians and nurses also continue to fear causing addiction in their patients, and patients and family members fear that they or their family members will become addicted.

The mistake of our society is that so much attention is paid to the small percentage of our population who have problems of addiction. There are far more citizens of Canada who live with a cancer diagnosis and other painful conditions than those who suffer from addiction to opioids. For all the campaigns against aberrant drug behaviour, our society is denied the information that morphines and other opioids have a very valuable and legitimate medical use. This is, in part, the reason for the fear that lies behind the physician's reluctance to prescribing opioids for pain. Further, the emphasis seems to be placed on the number of milligrams the patient is receiving. That is completely irrelevant. What is of the utmost importance is the effect.

Opioids are a treatment for pain, just as antibiotics are a treatment for infection or chemotherapy is a treatment for cancer. As such, with the education of how to treat pain and the knowledge of the pharmacokinetics of the opioids, I do not think there is any reason for the first of the recommendations, namely, that the Criminal Code be amended to clarify the practice of providing treatments for the purpose of alleviating suffering that may shorten life.

My first point is that pain is a condition that requires medical treatment. Treatment for any condition requires educated evaluation of the risk/benefit ratio.

Concerning the second recommendation, namely, the establishment of a set of guidelines for the provision of treatment for the purpose of alleviating suffering, where that may shorten life, to my knowledge I do not know of any such guidelines that have been established.

Regarding the third recommendation, that of education and training with respect to pain control, I think that we have a very long way to go. I am reminded on a daily basis that what I take as being very basic knowledge of pain control with the use of standard medications clearly poses enormous problems for many health care practitioners.

An important part of my job is in teaching primary and advance aspects of pain control for nurses and physicians. As part of those sessions, I always ask: Who has taken a course in pain management? I have yet to see one hand raised. I have a 30-year history working in palliative care. I am finding an increasing, albeit small, number of nurses who have had somewhat more time allotted to pain management education in their basic training programs. However, overall, the knowledge base required for good pain control is lacking. Mostly, I find that nurses base their practice on overt experience rather than educational knowledge. I often find the rationale of practice equivalent to, "Such and such worked for Mrs. White, therefore it will work for Mr. Black." This is hardly evidence-based practice, and it is something that we should be very concerned about.

Les médecins et les infirmiers et infirmières craignent encore de provoquer des toxicomanies chez leurs patients, et les patients et les membres de leurs familles craignent qu'eux-mêmes ou les membres de leurs familles ne deviennent toxicomanes.

Notre société a tort de s'en faire autant pour le petit pourcentage de la population qui a des problèmes de toxicomanie. Il y a beaucoup plus de citoyens au Canada qui vivent avec le cancer ou d'autres conditions douloureuses que de personnes qui souffrent d'assuétude aux opioïdes. Avec toutes ces campagnes que l'on mène contre les toxicomanies aberrantes, on omet de dire à notre société que la morphine et les autres opioïdes ont des usages médicaux très valables et légitimes. C'est cette crainte qui explique en partie l'hésitation des médecins à prescrire des opioïdes pour soulager la douleur. En outre, on semble accorder trop d'importance au nombre de milligrammes que le patient reçoit. Ce fait est totalement dénué d'importance. Ce sont les effets des opioïdes ici qui présentent la plus grande importance.

Les opioïdes soulagent la douleur, tout comme les antibiotiques guérissent les infections ou la chimiothérapie, le cancer. Ainsi, si l'on apprend comment traiter la douleur et si l'on connaît la pharmacocinétique des opioïdes, je juge inutile la première recommandation, à savoir que le Code criminel soit modifié afin de clarifier la situation concernant l'administration d'un traitement destiné à soulager la souffrance au risque d'abrégé la vie.

Je tiens à dire d'abord que la douleur est une condition qui exige un traitement médical. Le traitement pour toute condition exige une appréciation informée du ratio risque-avantage.

Pour ce qui est de la deuxième recommandation, à savoir que l'on élabore des lignes directrices sur l'administration de traitements visant à atténuer la souffrance mais susceptibles d'abrégé la vie, on n'a pas établi de telles lignes directrices à ma connaissance.

Pour ce qui est de la troisième recommandation, celle qui concerne la formation en matière de traitement de la douleur, je pense que nous avons beaucoup à faire de ce côté. Je constate tous les jours que ce que je considère être une connaissance très élémentaire du traitement de la douleur à l'aide des médicaments courants pose de toute évidence d'énormes problèmes pour bon nombre de praticiens de la santé.

L'enseignement aux infirmiers et infirmières et aux médecins du traitement de la douleur, aux niveaux élémentaire et avancé, est un volet important de mon travail. Dans le cadre de mon enseignement, je demande toujours aux participants: qui a suivi un cours en traitement de la douleur? Je n'ai jamais vu une seule main se lever. Et il y a trente ans que j'oeuvre dans le domaine des soins palliatifs. Je constate qu'un nombre croissant mais toujours insuffisant d'infirmiers et d'infirmières reçoivent une formation un peu plus poussée en traitement de la douleur dans le cadre de leur programme de formation de base. Toutefois, en règle générale, ces infirmiers et infirmières ne disposent pas des connaissances élémentaires qui sont requises pour un bon traitement de la douleur. Je constate surtout qu'ils fondent leurs pratiques sur l'expérience plutôt que sur le savoir. On explique souvent la raison d'être d'une pratique à peu près en ces termes:

I am aware of the education initiatives for physicians in palliative care; however, there are very few courses for nurses to learn pain and symptom management and palliative care. Much of the education on pain control and pain management for physicians and nurses is left in the hands of drug companies. Moreover, there are no training programs for nurse consultants in the clinical application of symptom control and palliative care practices. Indeed, I have had to seek my own training outside of Canada.

Nurse consultants in palliative care should be the role models and educators for those working with the terminally ill. Experiential learning is only as good as the education that underpins it. If the experts are denied education, then how can we possibly increase symptom knowledge for nurses in the community or in the hospital? I will extend that to physicians because I have a great deal of working knowledge with the physicians and advise them on symptom management a great deal. No wonder nurses feel that they have brought about a patient's death because they have administered the last shot of morphine. The bottom line is: We cannot stop our patients from dying. They die from their disease, not the last shot of morphine that may have brought relief in the patient's last couple of hours of life.

In terms of sedation practices, I think there have been some changes, and for the better. In 1996, Dr. Chater, myself, Judi Paterson, who was a clinical nurse specialist in palliative care at the time, and Dr. Viola undertook a research project to determine the origins of the term "terminal sedation;" to obtain the opinions of world experts on sedation practices and whether or not those experts had sedated patients, what medications they used, how successful the treatments were and, most important, whether or not these experts supported euthanasia and assisted suicide.

The following is actually from the abstract of that research project. I believe it is a pivotal project. We sent a postal survey to 61 selected palliative care experts. There were 59 physicians and two nurses. Neither of those nurses was from Canada. We were seeking their response to a proposed definition of "terminal sedation," to estimate the frequency of this practice, the reasons for its use, to identify the drugs and dosages used, to determine the outcome, and to explore the decision-making process. Opinions on physician-assisted suicide and voluntary euthanasia were also sought. About 87 per cent of the experts responded from eight countries, although predominantly from Canada and the United Kingdom. Forty per cent agreed unequivocally with our proposed definition; 4 per cent disagreed. About 89 per cent

«Tel ou tel traitement a réussi avec Mme Leblanc, par conséquent, ça sera bon pour M. Lebrun.» Il s'agit là d'une pratique aux fondements très incertains, et cela est très préoccupant.

Je suis au courant des initiatives éducatives s'adressant aux médecins chargés des soins palliatifs; cependant, il existe très peu de cours pour les infirmiers et infirmières en matière de soins palliatifs et de maîtrise des symptômes et de la douleur. L'éducation en matière de maîtrise et de traitement de la douleur pour les médecins et les infirmiers et infirmières est confiée dans une large mesure aux entreprises pharmaceutiques. En outre, il n'existe pas de programmes de formation pour les infirmiers et infirmières-conseils en matière d'application clinique des pratiques relatives au contrôle des symptômes et aux soins palliatifs. J'ai dû moi-même obtenir ma formation à l'extérieur du Canada.

Les infirmiers et infirmières-conseils chargés des soins palliatifs devraient être des modèles et des éducateurs pour ceux qui oeuvrent auprès des patients en phase terminale. L'apprentissage expérientiel n'a de valeur que s'il s'appuie sur une bonne formation. Si l'on n'éduque pas les experts, alors comment peut-on accroître la connaissance des symptômes pour les infirmiers et infirmières en milieu communautaire ou hospitalier? J'en dirai autant pour les médecins étant donné qu'il y a longtemps que je travaille avec eux et les conseille souvent en matière de maîtrise des symptômes. On ne s'étonne donc pas qu'un infirmier ou une infirmière s' imagine avoir causé la mort d'un patient parce qu'il ou elle lui a administré la dernière piqûre de morphine. Le fait est qu'on ne peut pas empêcher nos patients de mourir. Ils meurent de la maladie qu'ils ont contractée et non de la dernière injection de morphine qui les a soulagés pendant les quelques dernières heures de leur vie.

Pour ce qui est des pratiques sédatives, je pense que l'on a apporté des changements dans le bon sens. En 1996, le Dr Chater, moi-même, Judi Paterson, qui était alors infirmière clinique spécialisée en soins palliatifs, et le Dr Viola avons entrepris un projet de recherche pour connaître les origines de l'expression «sédation terminale» et pour solliciter les opinions d'experts mondiaux en matière de pratiques sédatives; nous voulions savoir aussi si ces experts avaient administré un traitement sédatif à leurs patients, quels médicaments ils avaient utilisés, dans quelle mesure les traitements avaient réussi et, le plus important, si ces experts étaient en faveur ou non de l'euthanasie et de l'aide au suicide.

Je vais vous présenter le résumé des conclusions de ce projet de recherche. Je dirais que c'est une étude de base. Nous avons envoyé un questionnaire par la poste à 61 experts en soins palliatifs présélectionnés. Il y avait 59 médecins et 2 infirmières. Aucune de ces infirmières n'était du Canada. Nous voulions savoir ce qu'ils pensaient d'une définition que l'on proposait de la «sédation terminale»; nous voulions estimer la fréquence de cette pratique et les raisons de son utilisation; nous voulions connaître les médicaments et les dosages utilisés, en connaître les résultats et examiner le processus décisionnel. Nous leur avons également demandé leur opinion sur l'aide médicale au suicide et l'euthanasie volontaire. Environ 87 p. 100 des experts ont répondu; ils provenaient de huit pays mais surtout du Canada et



reported using terminal sedation in the last 12 months — and over half of these for up to four patients. Reasons for using these methods included various physical and psychological symptoms.

The most common drugs used were midazolam and methotrimeprazine. Neither of these drugs are opioids, but rather anxiolytics, drugs that take away fear and suffering. They are indeed very comforting medications. Decision making involved the patient, the family and various aspects of the ease with which decisions were made. The use of sedation was perceived to be successful in 90 out of 100 patients. Ninety per cent of respondents did not support legalization of euthanasia, and I think that is a very important point.

In conclusion, sedation agents are used by palliative care experts as tools for the management of symptoms. The term “terminal sedation” should be abandoned and replaced with the phrase “sedation for intractable distress in the dying.” I do not know why the Senate committee used the term “total sedation.” I have no rationale for the use of that term.

We are all very busy, but it behooves us to hear the poignant story of why we decided to do that research project. It is a very personal experience of mine. I had the privilege of caring for a patient who had very extensive disease from renal cancer, a gentleman in his mid-50s. He had developed disease in his neck and his spine. He was seen by all the relevant experts and everyone agreed that this man should have surgery to stabilize his neck and relieve his excruciating pain.

The surgery was not curative but rather palliative. He was then to have radiation therapy. This is all very good medicine. The patient had surgery to have rods inserted into the vertebrae. Although his pain was difficult to control post-operatively, we had wonderful expert advice from the anaesthetist and we were well on the way to making him comfortable as he recovered.

Unfortunately, a short time after his surgery, the spinal rods became infected and the patient's pain rose accordingly. The doses of medications were increased appropriately, rotation of opioids was done as side effects from the morphine became problematic. In other words, all the right things were being done for this patient. The anaesthetic department was involved; palliative care and pastoral care was involved, but this man's pain continued to rise. We could not control it.

This patient was a big man and he had a big voice and he would cry out. The nursing staff were wonderful to him and the

du Royaume-Uni. Quarante pour cent approuvaient sans réserve la définition que nous proposons; 4 p. 100 n'étaient pas d'accord. Environ 89 p. 100 ont dit avoir recouru à la sédation terminale au cours des 12 derniers mois précédents — et plus de la moitié d'entre eux l'avaient administrée à quatre patients au maximum. Au nombre des raisons invoquées pour l'utilisation de ces méthodes, il y avait divers symptômes physiques et psychologiques.

Les médicaments utilisés le plus fréquemment étaient la midazolam et la méthotrimeprazine. Ce ne sont pas des opioïdes mais plutôt des anxiolytiques, donc des médicaments qui suppriment l'anxiété et la souffrance. Ce sont en effet des médicaments aux effets très bénéfiques. Le processus décisionnel faisait intervenir le patient, la famille, et les experts ont fait état des divers degrés d'aisance avec lesquels les décisions étaient prises. Pour 90 patients sur 100, le recours à la sédation était considérée comme une bonne chose. Quatre-vingt-dix pour cent des répondants n'étaient pas en faveur de la légalisation de l'euthanasie, et je pense que c'est là un fait très important.

En conclusion, les experts en soins palliatifs utilisaient des agents sédatifs pour traiter les symptômes. Il faut abandonner l'expression «sédation terminale» et la remplacer par l'expression «sédation soulageant la détresse réfractaire chez les mourants». J'ignore pourquoi le comité sénatorial employait l'expression «sédation totale». Je ne comprends pas du tout pourquoi on a utilisé ce terme.

Je sais que vous êtes tous fort occupés, mais je crois utile de vous raconter ce récit poignant qui nous a décidés à entreprendre ce projet de recherche. Il s'agit d'une expérience que j'ai vécue de très près. J'ai eu le privilège de soigner un patient qui était atteint d'un cancer aux reins très avancé, un monsieur dans la cinquantaine. Sa maladie s'était étendue à son cou et à son épine dorsale. Il avait été vu par tous les experts, et chacun était d'accord pour faire opérer cet homme afin de stabiliser son cou et soulager la douleur intolérable qu'il éprouvait.

L'intervention chirurgicale n'était pas curative mais plutôt palliative. Il devait ensuite se prêter à une radiothérapie. Le tout était très bien pensé. On a opéré le patient pour lui insérer des tiges dans les vertèbres. Même si l'on avait du mal à maîtriser sa douleur après l'opération, l'anesthésiste nous avait donné d'excellents conseils et nous étions sur le point de calmer sa douleur.

Malheureusement, quelque temps après l'intervention chirurgicale, les tiges dans son épine dorsale ont causé une infection et la douleur du patient s'est accrue en conséquence. Les doses de médicaments ont été augmentées comme il se devait, et on lui a administré des opioïdes en rotation étant donné que les effets secondaires de la morphine commençaient à faire problème. Autrement dit, on a fait tout ce qu'on devait faire pour ce patient. Le service d'anesthésie est intervenu; l'unité des soins palliatifs et le service d'aumônerie sont intervenus aussi, mais la douleur de cet homme ne cessait de croître. Nous ne pouvions plus la maîtriser.

Ce patient était un colosse, il avait une voix forte, et il hurlait. Les infirmières ont été admirables, avec lui et sa famille. Elles ont



family. They did all they could to comfort him. They kept at the physicians: Is there nothing more we can do?

Eventually, the suffering extended to the nursing staff and the attending physicians. Some nurses could not handle looking after the patient because they were having nightmares. Some staff were selected to provide at least some continuity of care for this man. The patient continued to cry out and to call out. He would shout, and I can assure you this was very loud, "If I were a dog, you would shoot me. Help me. Please help me."

The discussion then arose around sedating this man to relieve his suffering. The decision was made that to administer sedation to relieve his suffering was tipping the balance of the slippery slope argument of euthanasia. As a consequence, this patient died screaming. He never did go into a coma. He died crying for God to help him.

The nurses who cared for him required some counselling, and it was offered but little was actually provided. It is something that, even some eight years later, causes distress to those who were involved, and I include the physicians, the chaplains and all those involved in this case.

I do not think this situation would happen today. I think all involved would be willing to sedate this patient. Often, we find that sedating a patient even for a short while can abort the spiral of pain that is a combination of physical pain, fear of increasing or recurring pain, and emotional suffering and spiritual distress.

In conclusion, I will repeat, sedating agents are used by palliative care experts as tools for the management of symptoms. The term "terminal sedation" should be abandoned and replaced with the phrase "sedation for intractable distress in the dying."

**The Chairman:** Thank you for your presentation.

**Mr. David Roy, Clinical Research Institute of Montreal:** Honourable senators, a brief consensus has emerged over the last 20 years with respect to withholding and withdrawing life-prolonging treatments. Several difficult situations can be identified in which these decisions must be made.

I will make a brief comment on the ethics of managing pain and anguish. I will also reflect on how we forget the past — which should be to our chagrin — and I refer here to the recommendations, which seem to be totally covered with dust, of the Law Reform Commission of Canada in 1983. That document should be dusted off and brought back in front of us.

My next point will deal with palliative care, palliative medicine education and research, which seems to be dwindling and dwindling. Where have all the flowers gone? Well, my question will be: Where have all the leaders gone? Or where will they come from?

Finally, I will comment on palliative care and palliative medicine in the home. Dying at home is not always pretty.

fait tout ce qu'elles ont pu pour le soulager. Elles ne cessaient de demander aux médecins: peut-on faire autre chose?

Sa souffrance a fini par s'étendre au personnel infirmier et aux médecins traitants. Certaines infirmières ne pouvaient plus le regarder parce qu'elles avaient des cauchemars. On a désigné à son service certaines infirmières pour lui offrir à tout le moins une certaine continuité dans les soins. Le patient continuait de hurler à l'aide. Il criait, à pleins poumons, je vous l'assure: «Si j'étais un chien, vous m'achèveriez. Aidez-moi. Par pitié, aidez-moi.»

On s'est alors demandé si l'on devait lui administrer un traitement sédatif pour soulager sa douleur. On a décidé que le fait de lui administrer un traitement sédatif qui soulagerait sa douleur nous engageait sur le terrain glissant de l'euthanasie. En conséquence, ce patient hurlait encore au moment de sa mort. Il n'est jamais entré dans le coma. Au moment de sa mort, il implorait Dieu de lui venir en aide.

Les infirmières qui l'ont soigné ont eu besoin de counselling, et on leur en a offert, mais en fait, on leur en a peu donné. C'est un épisode qui, même près de huit ans plus tard, cause de l'angoisse à ceux qui y ont pris part. Et cela comprend les médecins, les auxiliaires et tous ceux qui sont intervenus.

Je ne crois pas que cette situation se produirait aujourd'hui. À mon avis, tous les intervenants seraient disposés à administrer un traitement sédatif à ce patient. On constate souvent que le traitement sédatif, même bref, peut mettre fin à la spirale de la douleur, laquelle est un mélange de douleur physique, de crainte d'un retour ou d'une accentuation de la douleur, de souffrance psychologique et de détresse spirituelle.

Pour conclure, je répéterai que les sédatifs sont utilisés par les experts des soins palliatifs pour gérer les symptômes. Il faudrait cesser d'utiliser l'expression «sédation terminale» pour parler plutôt de «sédation soulageant la détresse réfractaire chez les mourants».

**Le président:** Merci de votre témoignage.

**M. David Roy, Institut de recherches cliniques de Montréal:** Honorables sénateurs, au cours des 20 dernières années, il s'est dégagé un consensus au sujet de l'abstention et de l'interruption de traitements qui prolongent la vie. Il existe plusieurs situations douloureuses dans lesquelles de telles décisions doivent être prises.

Je ferai une brève observation sur l'éthique du soulagement de la douleur et de l'angoisse. Je parlerai également de la façon dont nous faisons fi du passé — à notre détriment — et je parlerai des recommandations apparemment totalement reléguées aux oubliettes qu'avait formulées en 1983 la Commission de réforme du droit du Canada. Le rapport de cette commission devrait être sorti du tiroir et redistribué.

Je parlerai ensuite des soins palliatifs, de l'enseignement de la médecine palliative et de la recherche dans ce domaine, qui semble perdre constamment du terrain. Si certains demandent où sont donc passées les neiges d'antan, ma question à moi, c'est où sont passés tous les leaders et d'où les nouveaux viendront-ils?

Enfin, je parlerai des soins palliatifs et de la médecine palliative à domicile. Ce n'est pas toujours très beau de mourir chez soi.

A consensus has emerged that, although saving lives always has been and will remain a primary goal of clinical practice, the initiation and continuation of intensive life-prolonging procedures may indeed result in little more than a stretching out of the dying curve or an extension of an unbearable and unrelentingly miserable life. Ms Jarvis gave a couple of examples.

Since the beginning of the 1970s, and particularly 1976 with the famous Quinlan case in the United States, patients, families, nurses, doctors and people from all walks of life have been asking whether an extension of life to the bitter biological end is the right thing to do, particularly when the sick and the dying find the physical, emotional and personal costs of such treatment to be hardly bearable. A trend has developed over two decades and its direction is away from an ethic of prolonging life at all costs, particularly costs the patient cannot bear, towards an ethic of emphasizing the quality of life and of dying over the duration of life taken as an absolute value.

The contemporary clinical-ethical consensus about withholding and discontinuing life-prolonging treatments emerges from the realization that treatments are a means and their use is not an end independent of the clinical goals that a patient accepts and that clinicians can achieve. It is these clinical goals that should govern decisions about initiating or discontinuing treatments, recalling all the while that these goals vary along the course of the disease. They also vary from patient to patient, even when patients have identical or very similar clinical conditions.

It is the nature of the patient's response to treatment plans that indicates the appropriate time to "down regulate" intensive, life-prolonging care and to "up regulate" palliative care. The shift is rarely abrupt, rarely of the on/off binary kind of change. Moreover, certain interventions, such as radiotherapy or surgery, may serve curative clinical goals for some patients and palliative goals for others. The treatments are not rigidly put in boxes. They can be used for quite different purposes, depending upon the evolution of the patient.

In a long continuum of evolving disease and correspondingly changing clinical goals, moments are reached when it is clinically, ethically and legally justifiable to withhold or to discontinue clinical treatments such as resuscitation procedures, respiratory support, dialysis, antibiotics, antiviral treatments, chemotherapy, surgery, and assisted hydration and nutrition. The discontinuance of this last-mentioned intervention is still very controversial.

Some people, including physicians, nurses and other health care professionals, may still be quite unaware of this trend and consensus, and others may think this direction is simply wrong. Moreover, some particular cases, perhaps even many, would inevitably provoke — and a number of these cases always will — agonizing decisions and discussions, intricate deliberations and difficult decisions, if for no other reason than that persons, both in

Même si sauver des vies a toujours été le principal objectif des soins cliniques et le sera toujours, on reconnaît généralement maintenant que dispenser ou poursuivre des soins intensifs pour prolonger la vie n'apporte parfois qu'un prolongement de l'agonie d'une vie misérable et insupportable. Mme Jarvis en a donné quelques exemples.

Depuis le début des années 70, et plus particulièrement en 1976, grâce au célèbre cas Quinlan, aux États-Unis, les patients, les familles, les infirmiers et infirmières, les médecins et le grand public se demandent si c'est une bonne chose de prolonger la vie jusqu'à son issue biologique amère, surtout dans les cas où les malades et les mourants jugent insupportable le coût physique, émotif et personnel de tels traitements. Au cours des 20 dernières années, une nouvelle tendance s'est développée. Cette tendance s'écarte de l'éthique qui préconise le prolongement de la vie à tout prix, surtout dans le cas des patients qui ne peuvent le supporter, et favorise une éthique qui insiste sur la qualité de vie et qui accorde à la mort, durant la vie, une valeur absolue.

Le consensus actuel dans le domaine clinique et éthique au sujet de l'abstention et de l'interruption de traitements de survie vient de ce qu'on s'est rendu compte que les traitements sont des moyens et que leur usage n'est pas une fin en soi, une fin indépendante des objectifs cliniques qu'accepte le client et que les cliniciens peuvent réaliser. C'est sur ces objectifs cliniques que devraient se fonder les décisions sur le commencement ou l'interruption des traitements, sans oublier que ces objectifs peuvent varier selon l'évolution de la maladie. Ces objectifs varient également d'un patient à l'autre, même lorsque l'état clinique des patients est identique ou très semblable.

C'est la nature de la réaction du patient au plan de traitement qui indique quand le moment est venu de mettre la pédale douce sur les soins intensifs de survie et d'insister davantage sur les soins palliatifs. Cela se fait rarement de façon abrupte et irréversible. Toutefois, certaines interventions, dont la radiothérapie ou la chirurgie, peuvent permettre d'atteindre des objectifs cliniques de guérison auprès de certains patients, et des objectifs palliatifs auprès d'autres. Les traitements ne sont pas des formules coulées dans le béton. Ils peuvent servir à diverses fins, selon l'évolution de l'état du patient.

Dans toute l'évolution de la maladie et l'évolution correspondante des objectifs cliniques, il y a des moments où il est cliniquement, déontologiquement et légalement justifiable de s'abstenir d'offrir des traitements cliniques comme la réanimation, le support respiratoire, la dialyse, les antibiotiques, les traitements antiviraux, la chimiothérapie, la chirurgie, ainsi que l'hydratation et l'alimentation artificielle, ou de cesser d'offrir ces traitements. L'interruption de cette dernière intervention soulève encore fortement la controverse.

Certains, y compris des médecins, des infirmiers et infirmières et d'autres professionnels de la santé, ignorent encore cette tendance et ce consensus. alors que d'autres croient que cette orientation n'est pas souhaitable. De plus, dans certains cas, peut-être dans de nombreux cas, cette orientation peut provoquer inévitablement — mais ce sera toujours inévitable dans certains de ces cas — des discussions et des décisions très douloureuses,



their bodies and biographies, are simply too complex to be reduced to principles.

People who think that we can put the entire control of decision making in this utterly complex area into a few little principles that you then apply, or into a few articles of a piece of law that you then apply, are sadly mistaken. It is not that the principles are not required; it is not that the articles of law cannot be helpful. However, if we intend to micro-manage and micro-regulate decisions in this area, we will fail, as we should fail, in attempting to substitute articles of ethics or articles of law for clinical and personal and professional judgment. The difficulty, of course, is that when professional and clinical judgment is no longer adequately functioning, when clinical and personal and professional judgments are not properly educated, then we have problems. The tendency then is, "Give me a law, because the doctor's or the nurse's judgment is no longer working." That is not the approach to take.

You will always find individual professionals who make bad judgments. It is when you see a trend of bad judgments that absolutely major efforts will need to be made. Are we seeing trends of bad judgments? That is difficult to determine without extensive studies, and whether or not the extensive studies could ever uncover a trend in very bad judgments is another matter. However, when you have cases coming before the courts on a regular basis, when you have coroner's inquiries that must be mounted, and when you have families divided and torn against hospitals, then we had better start to look at whether or not medical and nursing education in the area of clinical ethics has somehow slovenly sloughed off and needs to be revived and rejuvenated. I think it has to be revived and rejuvenated because it is sloughing off down into the areas of a degree of neglect.

In the late 1970s and early to mid-1980s, centres for ethics started to arise in the universities in various areas. Clinical ethics courses, medical ethics and nursing ethics courses started to crop up all over the place. There was a passionate interest in getting doctors and nurses involved in the teaching of clinical ethics. We are starting to see now that the pioneers and the leaders that did this in the late 1970s and early and mid-1980s, even up into the 1990s, are all getting old. They are all approaching retirement. It is not so obvious that there are younger people coming up with the same passion, the same experience and the same skills to carry on these courses.

Paralleling the rise in centres for ethics was the rise of palliative care and palliative medicine here in Canada, or at least the beginning of the first centre that I started and directed in Montreal in 1976. We were just beginning to found and to stimulate palliative care in Canada. That gradually led to the establishment of a home care service. People came from all over the world to Montreal and then to Ottawa and then to other places in Canada to learn how to deliver palliative care and palliative medicine in hospices, in hospitals, and in the home.

des délibérations complexes et des décisions graves, si ce n'est que parce que ces personnes, dans leur corps et dans leur vécu, sont trop complexes pour être réduites à de simples principes.

Ils se trompent, ceux qui pensent qu'on peut résumer le contrôle de ces décisions dans un domaine aussi complexe à quelques petits principes qu'il suffit d'appliquer, à quelques articles de loi qu'il s'agit d'exécuter. Ce qu'il faut, ce ne sont pas des principes, non plus que des articles de loi. Si l'on veut microgérer et microréglementer les décisions dans ce domaine, nous courons à l'échec, et c'est normal, car vouloir substituer des principes d'éthique ou des articles de loi au jugement clinique, personnel et professionnel est peine perdue. Le problème, bien sûr, c'est que le jugement professionnel et clinique ne fonctionne pas toujours, que le jugement clinique, personnel et professionnel n'est pas toujours suffisamment éclairé. Dans ces cas, les gens réclament des lois, car ils estiment que le jugement des médecins ou des infirmiers et infirmières n'est pas acceptable. Ce n'est pas la bonne approche.

Il y aura toujours des professionnels qui porteront de mauvais jugements. C'est quand on constate une tendance constante au mauvais jugement qu'il est nécessaire d'agir. Constatons-nous des tendances au mauvais jugement? Il est bien difficile de le déterminer sans études approfondies, et il reste même à déterminer si des études approfondies peuvent permettre ou non de découvrir une tendance à de très mauvais jugements. Toutefois, lorsque les tribunaux sont constamment saisis de certaines causes, lorsqu'il est nécessaire de tenir des enquêtes de coroner, lorsque les familles sont divisées et s'opposent aux hôpitaux, il faut alors se demander si la formation des médecins et des infirmiers et infirmières dans le domaine de l'éthique clinique laisse à désirer et devrait être revue. J'estime qu'il faut revoir l'enseignement qui leur est dispensé car le laisser-aller dans ce domaine confine à la négligence.

De la fin des années 70 jusqu'au milieu des années 80, on a commencé à créer des centres d'éthique dans les universités de diverses régions. On a commencé à offrir un peu partout des cours d'éthique clinique, d'éthique médicale et d'éthique des soins infirmiers. On voulait absolument amener les médecins et les infirmiers et infirmières à enseigner l'éthique clinique. Mais on constate maintenant que les pionniers et les leaders de cette époque, jusqu'à ceux des années 90, prennent de l'âge. Ils approchent tous l'âge de la retraite. Il n'est pas certain qu'il y ait une relève partageant la même passion, la même expérience et les mêmes compétences pour continuer d'offrir cet enseignement.

Parallèlement à la création des centres d'éthique, il y a eu une augmentation de la médecine et des soins palliatifs au Canada, ou du moins la création du premier centre que j'ai mis sur pied et dirigé à Montréal, en 1976. À cette époque, on commençait à découvrir et à encourager les soins palliatifs au Canada. Cela a mené progressivement à la création d'un service de soins à domicile. Des gens des quatre coins du monde venaient à Montréal, puis à Ottawa, puis ailleurs au Canada, pour apprendre comment offrir des soins palliatifs et pratiquer la médecine palliative dans des hospices, des hôpitaux et au domicile des patients.



The Royal Victoria McGill Palliative Care Service closed down the home care service in 1997. It does not exist any more. I have seen people in the home. These were not the poorest of the poor, by any means, but they were in rural areas. The patient was sent back home to die from the cancer, with bottles of oral morphine and a few rigid instructions as to how to administer it. I went to one of these farmhouses, and it was a disaster to see the family totally torn apart, not knowing what to do. When they followed the strict regulations, the pain was crushing, and they did not dare to give more. About a week later, they called me and said, "We want to give it all. We can't take it any more. We just can't take it, and she can't take it." I scrummed around and found a doctor who would travel the two-and-a-half hours there to take care of the woman, but she died before he could even get in the car and leave the next morning.

That is only an anecdote, but we can move across Canada and look at those who are being asked now more and more to die at home. The ambulatory care movement, or, as the French would say, the "virage ambulatoire", is great for those who can walk but not so great for those who cannot. This area will need to be studied. How do people die in the home?

Another area that I am starting to organize now, along with a group of various kinds of scientists, is how the poor die in Canada. We do not know how the poor die in Canada, and I am not so sure we want to know either. Knowing how the poor die in Canada would be an implicit, mandative responsibility that would work through the professions and up through the ministries of health and right up to the top politicians. I am not too sure we want that mandate of responsibility to become too publicly well-known. It will require hard decisions about where we should be putting our resources. Should we be putting our resources in the building of massive, mega-hospitals with the most high-tech equipment, involving millions of dollars, when we are neglecting the much more widespread need for community care and home care at a very primary, simple level? I am not saying it is an either/or thing, but there is a danger that we are going for the bigger and the high-tech that we are ignoring the massive suffering that is taking place on the ground level.

When patients refuse treatment, we seem to think that there are no problems. The patient is clear, conscious, lucid and stable in their will. However, when clear, conscious, stable patients, young and beautiful on top of that, refuse life-prolonging treatments, sometimes clinical staff who become bonded to them find it extremely difficult. The *Nancy B.* case in Quebec in 1990-91 is an example of that.

Another area is when burdens are not proportionate to benefits. I will not have time to go through a whole range of cases, but everything I am saying here, though it was written down, was written down on the basis of 23 years of working at the bed-side, particularly in intensive care units, neuro-trauma units, and severe burn units. Consider the case of an 84-year-old woman with

Le Service de soins palliatifs du Royal Victoria McGill a cessé d'offrir des soins à domicile en 1997. Ce service n'existe plus. J'ai visité des patients chez eux. Ce n'était pas les plus pauvres, pas du tout, mais ils habitaient dans les régions rurales. Plus particulièrement, une patiente avait été renvoyée chez lui pour mourir du cancer. On lui avait remis de la morphine administrable par voie orale et des instructions très rigoureuses sur la façon de l'utiliser. J'ai visité une de ces fermes, et j'ai constaté que la famille était entièrement déchirée et qu'elle ne savait que faire. Lorsqu'on suivait strictement la posologie, le patient souffrait atrocement, mais la famille n'osait pas augmenter les doses. Une semaine plus tard, la famille m'a appelé et m'a dit qu'elle était prête à administrer tout le reste du médicament au patient, puisque ni elle ni le patient n'en pouvait plus. J'ai cherché et j'ai trouvé un médecin qui était prêt à faire deux heures et demie de route pour s'occuper de cette patiente, mais elle est morte avant qu'il puisse monter dans sa voiture pour aller la visiter, le lendemain matin.

Ce n'est qu'une anecdote, mais un peu partout au Canada, on demande maintenant de plus en plus aux gens de mourir chez eux. Le mouvement en faveur des soins ambulatoires ou, comme le diraient les francophones, le «virage ambulatoire», est une excellente chose pour ceux qui peuvent marcher, mais ce n'est pas si bien pour ceux qui ne le peuvent pas. C'est une question qu'il faudrait examiner. Comment les gens meurent-ils à la maison?

Un autre domaine sur lequel je commence à me pencher avec un groupe de chercheurs, c'est la façon dont les pauvres meurent au Canada. Nous ne savons pas comment les pauvres meurent dans notre pays et je ne suis pas certain que nous voulions vraiment le savoir. Si nous savons comment les pauvres meurent au Canada, cela confèrera une responsabilité implicite qui ira des professionnels de la santé aux plus hauts échelons de la classe politique en passant par les ministères de la Santé. Je ne suis pas certain que nous voulions que le public prenne trop conscience de cette responsabilité. Nous aurons des décisions difficiles à prendre quant à l'utilisation de nos ressources. Devrions-nous les consacrer à construire d'énormes hôpitaux dotés de l'équipement le plus perfectionné, à coups de millions de dollars alors que nous ne répondons pas à un besoin beaucoup plus répandu, un besoin primordial, celui des soins communautaires et des soins à domicile? Je ne dis pas qu'il faille choisir entre l'un ou l'autre, mais nous risquons de nous orienter vers les gros établissements sans tenir compte des énormes souffrances qu'éprouvent les gens.

Lorsque les patients refusent un traitement, nous semblons croire qu'il n'y a pas de problèmes. Le patient est conscient, lucide et déterminé. Néanmoins, lorsque des patients qui s'expriment clairement, qui sont pleinement conscients et stables, jeunes et beaux par-dessus le marché, refusent des traitements qui prolongeraient leur vie, le personnel clinique qui s'est attaché à eux trouve parfois cela extrêmement difficile. Le cas de *Nancy B.*, au Québec, en 1990-1991, en est un bon exemple.

Il y a aussi le cas où les inconvénients du traitement sont disproportionnés par rapport à ses avantages. Je n'ai pas le temps de citer de nombreux exemples, mais tout ce que je vous dis est le résultat de 23 ans de travail au chevet des patients, surtout au service des soins intensifs, au service de traumatologie ou dans le service des grands brûlés. Prenez l'exemple d'une femme âgée de

advanced Parkinson's disease, advanced senile dementia of the Alzheimer's type, and pneumonia. Did treatment of that pneumonia with antibiotics involve burdens that were beyond benefits? We thought so in the early 1980s. She was deteriorating more and more with bed sores and had no consciousness whatsoever. There were no family members. There was a three-hour debate about what to do. During that debate, a young doctor said that we must deliver the antibiotics, treat the pneumonia. I said, "Really? Are we in a garage? The carburetor is not working, so we are going to fix the carburetor. There is no engine, no pistons, no battery, no tires, nothing left on the car, but we are going to fix the carburetor? We have to look at the entire patient. We are not here to treat a lung; we are here to treat the human being." In the context of looking at the totality of the patient, a decision was taken that it would be cruel to treat pneumonia after pneumonia after pneumonia, treat the biology and forget the person. She got worse and worse and worse. She was already beyond any ability to tell us anything.

When burdens are not proportionate to benefits, we cannot codify a series of little rules that will tell you exactly what to do in every case.

You must have very inspired and long experienced-based judgment. That does not mean that some decisions will not be mistakes, or will not be on the borders of the grey area of not knowing whether or not we did the right thing. That is part of the practice of care for severely ill people, of not always being certain that you have done the right thing.

When treatments are bound to fail, there are situations where you keep pumping blood into people who continue to bleed. It is like facet water going right down the drain, which you will not be able to reverse. However, you might be able to stabilize a person long enough for them to achieve his or her life goals, as was done for a man who kept coming back for his transfusions as his periods of remission got shorter and shorter. The nurses were screaming at the doctor for doing the transfusions, and the doctor replied, "I'm not forcing him to come back here. He is coming back on his own accord. He's got something he wants to say achieve." This man came back for the last time, with his suitcase and his wife, and he said, "Now I have come to die here. I don't want any more transfusions, just keep me comfortable." What did he do? He was building a porch around an old Quebec house, and he would not die before that porch was built.

The treatments here served the man's life plans. It was not an overly aggressive and unjustified prolongation of life by any means. The contrary, of course, can take place when we push when we should not, when being alive is no longer meaningful.

I have worked on a great number of cases of vegetative state, what is called "persistent vegetative state." We should never use that phrase, but it is used even in the medical literature, so I will. It is persistent or permanent states of unawareness and unconsciousness. It is not coma. Coma is deep sleep with no wake

84 ans, qui présente un cas avancé de la maladie de Parkinson, de démence sénile du type Alzheimer et une pneumonie. Le traitement de sa pneumonie aux antibiotiques impose-t-il des inconvénients qui surpassent les avantages? C'est ce que nous pensions au début des années 80. La santé de cette patiente se dégradait, elle avait des escarres et elle n'était plus consciente de ce qui se passait autour d'elle. Elle n'avait aucune famille. Nous avons discuté de ce que nous devions faire pendant trois heures. Au cours de la discussion, un jeune médecin a dit que nous devrions lui administrer des antibiotiques pour traiter sa pneumonie. Je lui ai dit: «Vraiment? Sommes-nous dans un garage? Le carburateur ne fonctionne pas, nous allons donc réparer le carburateur. Il n'y a pas de moteur, pas de pistons, pas d'accu, pas de pneus, plus rien, mais nous allons réparer le carburateur? Nous devons examiner le patient tout entier. Nous ne sommes pas là pour soigner un poumon, mais pour traiter l'être humain.» Dans ce contexte, nous avons estimé qu'il serait cruel de soigner des pneumonies les unes après les autres, de traiter la biologie et d'oublier la personne. L'état de la patiente empirait. Elle ne pouvait déjà plus nous dire quoi que ce soit.

Lorsque les inconvénients l'emportent sur les avantages, nous ne pouvons pas codifier une série de petites règles qui vous diront exactement quoi faire dans chaque cas.

Vous devez porter un jugement fondé sur la réflexion et une longue expérience. Cela ne veut pas dire que vous ne commettrez pas d'erreurs ou que vous ne saurez pas exactement si vous avez bien agi ou non. Cela fait partie des soins aux personnes gravement malades. Vous n'êtes pas toujours certain d'agir comme il le faudrait.

Lorsqu'il est évident que le traitement sera inutile, il arrive parfois que vous pompiez du sang dans des gens qui continuent de saigner. C'est comme un robinet dont l'eau coule directement dans le drain sans que vous puissiez l'arrêter. Vous pourriez toutefois stabiliser le patient pendant suffisamment de temps pour qu'il réalise ses objectifs, comme on l'a fait pour un homme qui revenait constamment recevoir des transfusions au fur et à mesure que ses périodes de rémission raccourcissaient. Le personnel infirmier reprochait au médecin de faire ces transfusions, mais le médecin répondait: «Je ne l'oblige pas à revenir ici. Il revient de son propre gré. Il a quelque chose à terminer.» Cet homme est revenu pour la dernière fois, avec sa valise et accompagné de sa femme, en disant: «Je suis venu mourir ici. Je ne veux plus de transfusions, je compte seulement sur vous pour assurer mon confort.» Que faisait-il? Il construisait une véranda autour d'une vieille maison québécoise et ne voulait pas mourir avant que cette véranda ne soit construite.

Les traitements lui ont permis d'atteindre son objectif. On n'a pas cherché à prolonger sa vie de façon injustifiée, par n'importe quel moyen. C'est bien entendu le contraire qui peut se produire lorsque nous insistons pour prolonger la vie alors qu'il ne le faudrait pas, lorsqu'il ne vaut plus la peine de vivre.

J'ai travaillé à un grand nombre de cas d'état végétatif, que l'on appelle «état végétatif persistant». Nous ne devrions jamais utiliser cette expression, mais on s'en sert même dans la documentation médicale, si bien que je le ferai. Il s'agit d'un état d'inconscience persistant ou permanent. Ce n'est pas le coma. Le



cycles. In persistent vegetative state, which becomes permanent after a period of observation, it has been recommended by the British Association of Physicians that a period of 9 to 10 months be used to observe a patient with severe neurological damage. If over a period of 9 to 10 months there are no signs of awakening and, in fact, there are signs of cerebral deterioration that can be neurologically assessed, then the persistent vegetative state becomes permanent vegetative state. It is at that time, if not earlier, when decisions should be broached about whether or not to continue hydrating and artificially feeding a person. Those decisions are extremely difficult.

I have been in two situations where the whole family, together with the physicians and the nurses, decided that the key question was not, "Are we justified in continuing after 10 months," but "Are we justified in continuing?" The burden was on those who wanted to continue, and no one wanted to continue. The parents, the husband, and the children all asked to stop the feeding, and the woman died within approximately three days.

A year later, I was in an institution where there are many such young people, with severe neurological trauma; indeed, all permanent vegetative states. The families come and their own family member, and then they visit with the other families; it is a big community of vegetative state patients and their families. At one point, one of the families raised the question as to whether or not their son should have continued artificial hydration and nutrition, and no one knew what should be done. Everyone was torn apart. I was asked by one of the doctors who knew me and the family to come to the institution to about this situation. Before I went to that appointment, rumours began, to the effect that this guy is coming, he will stop everything; he will kill this boy. I did not know this. I went in, we talked for a long time, and then I started to get feedback from the nurses and from the other people working there. We all came to the realization that we could not, in those circumstances, stop the assisted nutrition and hydration because in that context it would have been equivalent to exploding a bomb. The boy died of total system collapse six months later.

The entire situation must be taken into account when you make these decisions. This is emerging now under the program that we started approximately five to six years ago, developing what an "ethics for complexity" means. An ethics for complexity cannot be reduced to a couple of rules and a couple of principles.

There is one last area on which I will comment briefly. When anguish or pain are overwhelming, the important thing is that all the pain control and anguish control, the drugs, the dosages, the frequency, and the routes of administration that are used, should serve the fundamental goal of maintaining, if possible, a person's consciousness, with enough space so that they can think and talk and go through the things they want to go through. If you do not do that, pain totally reduces that space of mind, so that there is no liberty to think of anything except the pain and/or the

coma est un profond sommeil sans période d'éveil. Dans le cas de l'état végétatif persistant, qui devient permanent après une période d'observation, la British Association of Physicians a recommandé une période d'observation de neuf à dix mois pour les patients présentant de graves lésions neurologiques. S'il n'y a aucun signe d'éveil au bout de neuf à dix mois et s'il y a des signes de détérioration cérébrale qu'il est possible d'évaluer neurologiquement, l'état végétatif persistant devient un état végétatif permanent. C'est alors, sinon plus tôt, qu'il faudrait décider de continuer ou non l'hydratation et l'alimentation artificielles d'une personne. Ce sont des décisions extrêmement difficiles à prendre.

J'ai connu deux cas où toute la famille a estimé, en accord avec les médecins et le personnel infirmier, que la principale question à se poser n'était pas: «Devrons-nous continuer au bout de dix mois?», mais «Devons-nous continuer?» C'était à ceux qui voulaient poursuivre le traitement qu'il revenait de justifier leur décision, mais personne ne voulait le poursuivre. Les parents, le mari et les enfants ont tous demandé que l'on cesse d'alimenter la patiente et cette dernière est morte au bout de trois jours environ.

Un an plus tard, j'étais dans un établissement où il y a un grand nombre de jeunes atteints d'un grave traumatisme neurologique; en fait, ils sont tous dans un état végétatif permanent. Les familles viennent visiter leurs parents et rendent ensuite visite aux autres familles. Vous avez là tout un groupe de patients en état végétatif et leurs familles. À un moment donné, une des familles a demandé s'il faudrait poursuivre l'hydratation et l'alimentation artificielles de son fils, mais personne ne savait ce qu'il y avait lieu de faire. Tout le monde était déchiré. Un des médecins qui me connaissait et connaissait la famille m'a demandé de venir le voir pour discuter du cas. Avant que je me rende dans l'établissement, des rumeurs ont commencé à circuler selon lesquelles j'allais venir tout arrêter et tuer ce garçon. Je ne le savais pas. Je suis allé là-bas, nous avons longuement discuté et j'ai ensuite commencé à recevoir des nouvelles du personnel infirmier et des autres personnes qui travaillaient dans l'établissement. Nous nous sommes tous rendu compte que, dans les circonstances, nous ne pouvions pas arrêter l'alimentation et l'hydratation artificielles, car dans les circonstances, cela aurait eu l'effet d'une bombe. Ce garçon est mort d'un arrêt total de ses fonctions vitales six mois plus tard.

Vous devez prendre ce genre de décision en tenant compte de la situation dans son ensemble. C'est ce qui ressort du programme que nous avons lancé il y a environ cinq ou six ans en développant une «éthique de la complexité». On ne veut pas réduire ce genre d'éthique à quelques règles et quelques principes.

C'est une des dernières questions dont je parlerai brièvement. Lorsque l'angoisse ou la douleur est trop intense, il faut que tout ce qui sert à l'atténuer, les médicaments, les dosages, la fréquence et la voie d'administration, visent à l'objectif fondamental qui est de maintenir, si possible, la personne en état de conscience pour qu'elle puisse réfléchir et parler librement. Si non, la douleur réduit totalement son espace mental au point de l'empêcher de penser à autre chose que la douleur et les symptômes qui l'accompagnent comme les vomissements, une fatigue excessive,



accompanying symptoms, such as vomiting, excessive fatigue, et cetera. There are other people for whom the only peace they can achieve is by not maintaining consciousness.

Some people need to sleep before they die. By saying the word "sleep", I am not using a euphoric term for euthanasia. They need to sleep before they die. Some people can be reawakened and stay awake for a while, some cannot. That was the point about pain and anguish.

I will finish by offering one recommendation with respect to the Law Reform Commission of Canada. In 1983, the Law Reform Commission of Canada made five recommendations as to how the Criminal Code should be amended. Two of the recommendations had to do with not de-criminalizing or legalizing euthanasia, and not de-criminalizing and not legalizing assisted suicide.

The third, fourth and fifth recommendations are, briefly, the following: Nothing in sections 14, 45, 198, 199 and 229 of the Criminal Code of Canada should be interpreted as requiring a physician — this is recommendation 3 — to continue to administer or to undertake medical treatment against the expressed wishes of the person for whom such treatment is intended; recommendation 4, nothing in those sections shall be interpreted as requiring a physician to continue to administer or to undertake medical treatment when such treatment has become therapeutically useless in the circumstances and is not in the best interests of the person for whom it is intended; and recommendation 5, nothing in the same sections of the Criminal Code shall be interpreted as preventing a physician from undertaking or obliging him or her to cease administering appropriate palliative care intended to eliminate or to relieve the suffering of a person, for the sole reason that such care or measures are likely to shorten the life expectancy of the person, a likelihood that is extremely exaggerated in the lay mind.

William Kerr, writing in the *New England Journal of Medicine*, contrasted that with a 600-page volume put out by the United States and referred to the beauty and simplicity of this document. He closed his article by stating that "states in our country that have not yet established ethical legal standards in this field would do well to study and consider the wisdom applied to these difficult issues by the Law Reform Commission of Canada."

Provinces, or even the federal Government of Canada, if they have not yet established ethical legal standards in this field, would do well to study and consider the wisdom applied to these difficult issues by the Law Reform Commission of Canada. That is David Roy, not William Kerr.

These guidelines for amending the code give wide space for clinical judgment. That space is necessary. That space will not be filled with adequate clinical judgment unless we get moving and organize the courses and the research. You cannot teach for very long if you do not do research. The courses and the research are needed for palliative care, palliative medicine and clinical ethics of palliative care and palliative medicine. As a matter of fact, those courses with examinable material, by and large, do not exist.

etc. Il y a d'autres personnes qui peuvent seulement trouver le repos en perdant conscience.

Certaines personnes ont besoin de dormir avant de mourir. Lorsque je parle de «dormir» ce n'est pas un euphémisme qui signifie euthanasie. Elles ont besoin de dormir avant de mourir. Certaines peuvent être réveillées et rester éveillées un instant, mais d'autres pas. Voilà ce que je voulais dire au sujet de la douleur et de l'angoisse.

Je terminerai en formulant une recommandation en ce qui concerne la Commission de réforme du droit. En 1983, la Commission de réforme du droit du Canada a fait cinq recommandations visant à modifier le Code criminel. Deux d'entre elles préconisaient de ne pas décriminaliser ou légaliser l'euthanasie et l'aide au suicide.

La troisième, la quatrième et la cinquième recommandation disaient en substance que les articles 14, 45, 198, 199 et 229 du Code criminel du Canada ne devraient pas obliger un médecin — c'est la troisième recommandation — à continuer d'administrer ou à commencer un traitement médical à l'encontre des désirs exprimés par le patient; selon la recommandation 4, ces articles ne devraient pas obliger un médecin à continuer d'administrer ou à commencer un traitement médical si ce traitement est devenu inutile dans les circonstances et n'est pas dans l'intérêt du patient et, dans la recommandation 5, on demande que ces articles ne soient pas interprétés de façon à empêcher un médecin de donner des soins palliatifs ou à l'obliger de cesser d'administrer des soins palliatifs appropriés pour éliminer ou soulager les souffrances d'une personne, pour la seule raison que ces soins ou ces mesures risquent d'abrégé sa vie, une probabilité qui est extrêmement exagérée dans l'esprit du profane.

William Kerr a, dans le *New England Journal of Medicine*, comparé ce document avec un volume de 600 pages publié par les États-Unis en soulignant sa beauté et sa simplicité. Il termine son article en disant que: «Les États de notre pays qui n'ont pas encore établi de normes d'éthique dans ce domaine feraient bien de s'inspirer de la sagesse avec laquelle la Commission de réforme du droit du Canada a examiné ces questions complexes.»

Les provinces ou même le gouvernement fédéral feraient bien, s'ils n'ont pas encore établi de normes d'éthique dans ce domaine, de s'inspirer de la sagesse avec laquelle la Commission de réforme du droit du Canada s'est penchée sur ces questions délicates. C'est David Roy qui vous le dit, et pas William Kerr.

Ces lignes directrices pour la modification du Code criminel laissent une large place au jugement clinique. C'est indispensable. La place ne sera pas faite à un jugement clinique adéquat à moins que nous n'organisions des cours et des recherches. Vous ne pouvez pas enseigner bien longtemps si vous ne faites pas de recherches. Les cours et la recherche sont nécessaires tant pour les soins palliatifs que pour la médecine palliative et l'éthique clinique des soins palliatifs et de la médecine palliative. En fait, ces cours n'existent pas de façon générale.

**The Chairman:** I wish to begin the questioning because I think there is a bit of difference between the evidence of the two witnesses, and perhaps we can resolve that before we move on. Ms Jarvis, you indicated that you did not think there was any need for changes in the law. Let me say that the 1995 report was in response to the Law Reform Commission's report, in which they said there needed to be some changes in the law. Dr. Roy seems to think there do need to be some changes in the law. Can we balance those two in some way?

**Ms Jarvis:** There was a change in the law with regard to pain control. In some ways, Dr. Roy and I agree, in that we must always consider the risk-benefit ratio. I do not feel that pain medications shorten life. There is no need to amend the Criminal Code because pain medications do not shorten life. We know that with the first dosage there is considerable risk, but that situation could apply to anyone who was going in to have surgery. That does not fall under palliative care.

The other risk is with increasing opioids too rapidly, and the problem there is ignorance. My point is that we need to have well-educated people who are able to make good, clinical judgments. In palliative care, we do not accept the side effects of opioids as the norm. We do not accept that, because it is very unpleasant. Just increasing opioids can cause seizures or other types of unpleasantness for patients. We do not want that.

If we are getting to the edge of where we cannot control pain, and I think we are doing better by using different agents, then we need to look at sedation practices, with everybody involved. However, do we need a law to acknowledge that these things actually shorten life? I am not so sure. It does not matter how hard we try, patients will die and we must accept that.

**The Chairman:** Taking aside the phrase "shorten life" — because Dr. Mount, by the way, has written to me in exactly the same way that you have expressed, that he does not like that phrase because he does not think it is applicable any longer. We also heard from Dr. Macdonald last week, who indicated that because of lack of training and lack of people with knowledge and expertise in the field, and pleading very hard for that knowledge and expertise, he is still of the view that the law needs to be changed because the vast majority of physicians who are doing end-of-life care are fearful of providing the drugs because of potential legal ramifications.

**Mr. Roy:** The sections of the Criminal Code, as they now stand, that were referred to by the Law Reform Commission could indeed be used against physicians, and they should be changed. They are totally outdated. That is not the question.

**La présidente:** Permettez-moi de poser la première question parce que je pense déceler une différence dans le témoignage de nos deux témoins et nous pouvons peut-être éclaircir cela avant d'aller plus loin. Madame Jarvis, vous avez dit qu'à votre avis, il n'était pas nécessaire de modifier les lois. Je vous rappelle que le rapport de 1995 a été rédigé en réponse au rapport de la Commission de réforme du droit qui préconisait une modification des lois. Le Dr Roy semble penser qu'effectivement, il faudrait modifier les lois. Comment concilier vos deux points de vue?

**Mme Jarvis:** La loi a été changée en ce qui concerne le traitement de la douleur. À certains égards, le Dr Roy et moi-même disons la même chose. Nous sommes d'accord pour dire qu'il faut toujours tenir compte de l'opposition risques-avantages. Selon moi, les analgésiques n'abrègent pas la vie. Point n'est besoin de modifier le Code criminel car les analgésiques n'abrègent pas la vie. Nous savons qu'il y a des risques considérables lorsqu'on administre la première dose mais cela est vrai dans le cas de quiconque va subir une chirurgie. Ce n'est pas spécifique aux soins palliatifs.

Un autre risque provient d'une augmentation trop rapide de la dose d'opioïdes et dans ce cas-là, c'est de l'ignorance. Je dis qu'il faut pouvoir compter sur du personnel bien formé capable de porter de bons jugements cliniques. Dans le cas des soins palliatifs, nous n'acceptons pas les effets secondaires des opioïdes comme un mal nécessaire. Nous n'acceptons pas cela car cela peut être très déplaisant. L'augmentation des doses d'opioïdes peut entraîner une crise cérébrale ou d'autres états déplaisants pour le patient. Nous voulons éviter cela.

Si on en arrive à ne plus pouvoir traiter la douleur — mais je pense que les choses s'améliorent parce que nous faisons appel à divers agents —, alors il faut se tourner vers les sédatifs, avec la participation de tous les intéressés. Toutefois, faut-il une mesure législative qui reconnaisse que ces moyens abrègent effectivement la vie? Je n'en suis pas sûre. Quoique nous tentions de faire, les patients vont mourir et nous devons accepter cela.

**La présidente:** Je reprends l'expression «abrèger la vie» — car le Dr Mount, soit dit en passant, m'a écrit une lettre qui va dans le même sens de ce que vous avez dit, c'est-à-dire qu'il n'aime pas cette expression car il ne pense pas qu'elle soit encore applicable aujourd'hui. La semaine dernière, nous avons entendu le témoignage du Dr MacDonald, qui nous a dit qu'à cause d'un manque de formation, d'un manque de compétence et d'expérience dans le domaine, il estime toujours que les lois doivent être modifiées car la vaste majorité des médecins qui s'occupent de patients à l'agonie craignent de leur administrer des médicaments à cause des conséquences juridiques potentielles mais il ajoute qu'il existe un besoin pressant du côté de la connaissance et des compétences en la matière.

**M. Roy:** Les articles du Code criminel, dans leur version actuelle, et auxquelles la Commission de réforme du droit se reporte, pourraient effectivement être utilisés contre les médecins et il faudrait les modifier. Ils sont tout à fait périmés. Mais là n'est pas la question.



The key question is: In what way should the laws be changed? If the legislation is changed with draft bills that try to micromanage, those bills will cause more trouble and concern than if they simply left the articles the way they are now.

The way the Law Reform Commission had suggested amending those sections was with the paragraphs that I just quoted to you. Those paragraphs left things wide open. If you start detailing, there must be two witnesses. One witness must sign here, the other consultant will be called upon here. Legislation that details procedure will never address the infinite variety of situations that may arise.

That is why some of the drafts that have been put forward have caused more concern amongst the physicians who have seen them than the actual articles as they now stand.

There is another reason, though, that we should very carefully to consider how the Canadian Criminal Code should be amended in these matters; that is, that the consensus that I spoke to you about at the very beginning of my remarks is a consensus that is widely held throughout North America. There are indications that consensus is beginning to break down in the United States over the last several years. In 1997, a doctor from Kansas was sent to prison for 30 months because he gave pain control medication to an elderly woman who was in considerable pain because of cancer and because he disconnected respiratory support for an elderly man who was an advanced diabetic who had a massive stroke that left him totally incapacitated. In Canada, similar decisions, taken in a clinical context, with proper communication between treatment staff and family, would lead to no legal suit in any sense whatsoever.

The case we heard about from Montreal was due to very poor communication between family and staff with respect to the disconnecting of the respirator from the patient. That led to enormous emotional and other kinds of difficulties.

At present, there is a trend in the United States for doctors to limit the prescription of adequate pain control medication because they are frightened they will be sued. Spending 30 months in jail does not help one's practice. The movement now taking place is towards a system of rigidly regulated clinical and medical practice in these areas of palliative medicine and intensive care. We must not ignore that movement; it could influence Canadian procedures.

With all the educational programs that we have to organize, with all the investigation as to how home care should be properly organized and financed, we must not ignore the fact that the Criminal Code could breathe a cold chill down the backs of people working in these areas.

**Senator Beaudoin:** I was impressed by your two presentations; they were right on point. The objective of this committee is clear-cut. We wish to give effect to the points on which the committee members were unanimous in the 1995 report.

La question centrale est la suivante: de quelle façon devrait-on modifier les lois? Si les lois sont modifiées ponctuellement, pour gérer les choses ponctuellement, ces modifications vont faire plus de dégâts et causer plus d'inquiétude que si l'on maintenait la version actuelle de ces articles du Code criminel.

La Commission de réforme du droit a proposé de modifier ces articles en utilisant les énoncés que je viens de vous citer. Ce libellé est tout à fait général. Si l'on devient trop minutieux, on exige deux témoins, il y en a un qui doit signer ici, et l'autre médecin consultant sera appelé à signer ailleurs. Les mesures législatives qui prévoient une procédure détaillée n'arriveront jamais à couvrir la gamme infinie de situations qui peuvent se présenter.

Voilà pourquoi certaines propositions ont causé plus d'inquiétude chez les médecins que les articles actuels du Code criminel.

Il y a une autre raison pour que nous soyons très prudents si nous envisageons de modifier le Code criminel à cet égard. Je vous ai parlé tout à l'heure d'un consensus qui semble assez général en Amérique du Nord. Depuis quelques années, cette unanimité s'effrite aux États-Unis. En 1997, un médecin de l'État du Kansas a purgé 30 mois de prison parce qu'il avait donné un médicament contre la douleur à une vieille dame qui souffrait énormément du cancer et parce qu'il avait débranché l'appareil de survie respiratoire d'un homme âgé diabétique qui avait subi un accident cérébrovasculaire qui l'avait frappé d'incapacité. Au Canada, des décisions semblables prises dans un contexte clinique, avec les communications qui s'imposent entre le personnel soignant et la famille, n'aboutiraient absolument pas à des poursuites judiciaires.

Ce que nous avons entendu dire à Montréal est qu'il y avait eu de bien piètres communications entre la famille et le personnel soignant quand il s'est agi de débrancher le respirateur artificiel. Cela a entraîné de vives émotions et toutes sortes de difficultés.

Pour l'instant, les médecins américains ont tendance à restreindre l'ordonnance d'analgésiques car ils craignent d'être poursuivis en justice. Trente mois de prison, ce n'est pas une très bonne publicité pour un médecin. La tendance actuelle va dans le sens d'un système de pratique médicale et clinique doté de règles rigides quand il s'agit de médecine palliative ou de soins intensifs. Il ne faut pas fermer les yeux là-dessus car ce mouvement pourrait influencer les procédures canadiennes.

Toutes sortes de programmes éducatifs devront être mis en place, toutes sortes d'analyses sur la façon dont les soins à domicile devront être organisés et financés devront être effectuées et il ne faut donc pas, dans ce contexte, oublier que le Code criminel pourrait rendre très frileux les gens qui travaillent dans ces secteurs.

**Le sénateur Beaudoin:** Vos deux exposés m'ont beaucoup impressionné. Vous êtes allés au cœur du sujet. Le but de notre comité est très net. Nous voulons mettre en vigueur les éléments du rapport de 1995 sur lesquels les membres du comité étaient unanimes.



You appeared before the previous committee, Dr. Roy, and I remember everything you said. The difficulty for this committee is to put those unanimous points into law. One of the most difficult things in the world is to draft a perfect law.

The Criminal Code is an even more difficult situation because within that body of laws we must be precise. When we are precise, the risks are that the legislation will not be adequate after a certain time.

Dr. Roy, you referred to the *Nancy B.* case. I think that was a good decision. I do not have any problem with withholding of treatment or refusal of treatment or withdrawal of instruments. We all agree on that. However, the way to reflect the opinions of *Nancy B.* in our legislation worries me. You seem to have some doubt about the consequences of the *Nancy B.* case. I should like to know more about what you have in mind.

**Mr. Roy:** I have no doubts about the decision in that case. In my opinion, it was one of the best decisions we have had in Canadian jurisprudence. The only other decision that had the same power was the *Stephen Dawson* decision in the British Columbia Court of Appeal in the 1980s. In that case, the first court wanted to justify the parents' request that all treatment be withheld from Stephen, who had an infection from a shunt for hydrocephalus. The shunt had to be removed and cleaned and a new one put in. Of course, the boy would have died. The first court agreed with the parents that the patient's life was miserable. The second court got better testimony from the doctor, who knew Stephen personally. That court found that the descriptions of Stephen in the first case did not correspond to the real Stephen. The descriptions made his life so poor and miserable that reading that you would say, "Let him go." Those who knew Stephen, however, said, "No, he is not that bad."

I met Stephen about 14 years later, when I was working with another doctor who was looking at babies who had suffered as a result of their mothers taking drugs during pregnancy. He took me in to see Stephen, who was about 21 at the time. He was, of course, very mentally damaged. However, he was a very affectionate boy. He came up to me, threw his arms around my neck and hugged me. There were people who wanted to make everyone believe that his life was not worth living. He was watching television by himself that day.

*Nancy B.* was suffering from Guillain-Barré syndrome, which causes total paralysis. She could not do anything for herself. She could not wipe the rolling sweat off her brow in the hot summer. She requested through various signals that she wanted her respiratory support stopped. Her parents concurred. The hospital did not know what to do. The ethics committee was divided. Finally, the case went to the courts. Justice La Forest explained in his judgment that withdrawing respiratory support in this case would be neither homicide nor suicide. He clearly distinguished them and referred to the Law Reform Commission documents that I have just cited. He used them in great part as the basis for his judgment. I have no reservations with this judgment at all. In fact,

Docteur Roy, vous avez déjà comparu devant le comité et je me souviens très bien de ce que vous avez dit. La difficulté en ce qui nous concerne est de traduire les opinions unanimes en une mesure législative. Une des choses les plus difficiles du monde est de rédiger un texte législatif parfait.

Le Code criminel rend les choses encore plus difficiles car dans ce cas-là il nous faut être précis. La précision comporte le risque que la loi soit insuffisante après un certain temps.

Docteur Roy, vous avez parlé de l'affaire *Nancy B.* Je pense que c'était une bonne décision. Je ne vois pas d'inconvénient à ce que l'on interrompe ou on refuse un traitement de survie. Nous sommes tous d'accord là-dessus. Toutefois, la façon de transcrire les opinions que contient la décision *Nancy B.* dans nos lois m'inquiète. Vous semblez avoir un certain doute à l'égard des conséquences de l'affaire *Nancy B.* Pouvez-vous développer votre pensée?

**M. Roy:** Je ne vois absolument rien à redire à cette décision. À mon avis, c'est l'une des meilleures décisions de la jurisprudence canadienne. La seule autre qui ait le même pouvoir est la décision *Stephen Dawson*, de la Cour d'appel de la Colombie-Britannique dans les années 80. Dans cette affaire, le tribunal de première instance a voulu justifier la requête des parents portant que l'on interrompe tout traitement de Stephen, qui était infecté par la sonde utilisée pour traiter son hydrocéphalie. Il fallait retirer la sonde pour la nettoyer et en remettre une nouvelle. L'enfant aurait pu mourir. Le tribunal de première instance a convenu avec les parents que la vie du patient était misérable. Au palier suivant, la cour a obtenu un meilleur témoignage de médecins qui connaissaient Stephen personnellement. La cour a déterminé que la description de la vie de Stephen dans le premier cas ne correspondait pas à la réalité. La description qu'on avait faite était si misérable qu'en lisant les détails, on se disait: «Qu'on le laisse aller.» Ceux qui connaissaient Stephen, toutefois, ont dit: «Non, il n'est pas si misérable que cela.»

J'ai rencontré Stephen 14 ans plus tard, lorsque je travaillais avec un autre médecin qui étudiait les bébés nés de mères ayant absorbé des drogues pendant leur grossesse. Ce médecin m'a amené voir Stephen qui avait environ 21 ans à ce moment-là. Il est vrai qu'il était aux prises avec de graves difficultés mentales. Toutefois, c'était un garçon affectueux. Il s'est approché de moi et, m'entourant de ses bras, il m'a fait un câlin. Il y a des gens qui voulaient faire croire à tout le monde que sa vie ne valait pas la peine d'être vécue. Ce jour-là, il regardait la télévision seul.

*Nancy B.* souffrait du syndrome Guillain-Barré, qui entraîne une paralysie totale. Elle ne pouvait rien faire seule. Elle ne pouvait même pas essuyer les gouttes de sueur qui tombaient de son front l'été. Par divers signaux, elle a signifié qu'elle voulait que l'on débranche son respirateur artificiel. Ses parents ont accepté. L'hôpital ne savait pas quoi faire. La commission d'éthique était partagée. Finalement, l'affaire a été entendue au tribunal. Le juge La Forest a expliqué dans son jugement que de débrancher le respirateur artificiel dans ce cas-là ne constituerait ni un homicide ni un suicide. Il a fait une distinction très claire entre les deux et s'en est référé aux documents de la Commission de la réforme du droit que je viens de citer. Il s'en est inspiré

it is a judgment that has set ethical precedent in the clinical world, at least in Quebec.

**Senator Beaudoin:** What is difficult is the equilibrium between what the medical experts are thinking and what the Criminal Code says. I agree with you, we should give a great deal to the medical experts. They should have some leeway. However, we have to put in place some parameters for the protection of everyone. Are you saying that the doubt should be in favour of the doctors and the nurses? Am I to conclude that the Criminal Code should not intervene too much, but be in place merely as a guardian, because the situation evolves from years to year? We are no longer in 1995. Perhaps we have come to some other conclusions. In other words, the whole debate is between those who say, "Leave it to the courts and to the doctors," and those who say, "Enact good legislation and try to find an equilibrium between what the law is saying and what the medical experts are thinking."

**Mr. Roy:** I am not a lawyer and I have no idea as to how to write legislation. How should we change it, and in what directions? Excuse me for citing this document again, something that I have used in teaching for almost 23 years. I have used it in clinical ethics courses across the country and in other countries. If someone told me I had but three minutes to answer the question, "In what direction should we go?", I would say, "Follow the direction in this document." They are extremely simple statements, but they contain very clear parameters. They do not suffocate families and professional staff when they have to make these decisions.

It involves not just doctors. There is a judicial model in which the decision will be taken by judges or a semi-official body such as an ethics committee. Then there is the family model, in which the family decides. Then there is the medical model, in which the doctors decide. Neither of those models is adequate. What in practice is evolving, and where it works the best, is when doctors and nurses, who see the patient most of the time, get together to work out these decisions. When that works, it works beautifully. It does not always work because families are frequently divided right down the middle. In some cases, you have to go to the courts — and the courts are there for that.

If we could amend the law to take into account the committee's unanimous recommendations, as well as have an interpretive section that would state that, normally, these decisions should be taken by treating physicians and clinical staff, together with family, if the patient is unconscious, and that the courts are there when people cannot agree, we would be 95 per cent ahead of ourselves. If we try to micromanage a piece of legislation, it will simply not work.

largement pour écrire son jugement. Je ne vois rien à redire à ce jugement. En fait, c'est un jugement qui a établi un précédent déontologique en médecine clinique, du moins au Québec.

**Le sénateur Beaudoin:** Ce qui est difficile, c'est de trouver le juste milieu entre ce que pensent les professionnels de la santé et ce que dit le Code criminel. Je suis d'accord avec vous pour dire qu'il faudrait s'en remettre dans une large mesure aux professionnels de la santé. Ces spécialistes devraient avoir une certaine latitude. Nous devons toutefois fixer des paramètres afin d'assurer la protection de tous. Voulez-vous dire qu'en cas de doute il faudrait pencher du côté des médecins et du personnel infirmier? Dois-je conclure que le Code criminel ne devrait pas trop intervenir, mais qu'il devrait simplement servir de garde-fou, puisque la situation évolue d'une année à l'autre? Elle n'est plus ce qu'elle était en 1995. Nous en sommes peut-être arrivés à d'autres conclusions depuis. Autrement dit, la polémique s'est engagée entre ceux qui disent: «Qu'on s'en remette aux tribunaux et aux médecins», et ceux qui disent plutôt: «Adoptons de bonnes lois et cherchons à trouver un équilibre entre ce que dit la loi et ce que pensent les professionnels de la santé».

**M. Roy:** Je ne suis pas avocat et je ne sais pas du tout comment on s'y prend pour rédiger les lois. Quelles modifications faudrait-il y apporter, et dans quel sens faudrait-il se diriger? Pardonnez-moi de citer encore une fois ce document, dont je me sers dans mes cours depuis près de 23 ans. Je m'en sers dans les cours d'éthique clinique que je donne au Canada et à l'étranger. Si on me disait que je n'avais que trois minutes pour répondre à la question «Dans quel sens devrions-nous nous diriger?», je dirais: «Suivez le sens proposé dans ce document.» Les principes qui y sont énoncés sont très simples, mais ils constituent des paramètres très clairs. Ils n'étouffent pas les familles et les professionnels qui sont appelés à prendre de ces décisions.

Les médecins ne sont pas les seuls à avoir leurs mots à dire. Dans le modèle judiciaire, la décision est prise par un juge ou par un organisme quasi officiel, comme un comité d'éthique. Selon le modèle familial, c'est la famille qui décide. Il y a aussi le modèle médical, où ce sont les médecins qui décident. Aucun de ces modèles ne suffit à lui seul. Ce qui se fait de plus en plus, et ce qui donne les meilleurs résultats, c'est que les médecins et le personnel infirmier, qui passent le plus de temps avec le patient, se réunissent pour prendre ces décisions. Ce modèle, quand il fonctionne, donne des résultats incomparables. Il ne fonctionne pas toujours, parce que, bien souvent, les familles sont divisées en deux camps. Dans certains cas, il faut s'adresser aux tribunaux — et les tribunaux sont là pour cela.

Si nous pouvions modifier la loi pour tenir compte des recommandations unanimes du comité et pour y inclure aussi une disposition d'interprétation qui prévoirait qu'en temps normal, ces décisions devraient être prises par les médecins et le personnel clinique soignants, de concert avec la famille si le patient n'est pas conscient, et que les tribunaux n'interviendraient que dans le cas où on n'arriverait pas à s'entendre, ce serait déjà un progrès formidable. Il serait futile d'opter pour la microgestion par la voie législative.



**Ms Jarvis:** I would like to make one comment in relation to the phrase “to shorten life” and the differences between Drs. Macdonald and Mount. Not having enough education is not a good reason to change the Criminal Code, because you need knowledge to know how to administer these medications. If the education is not there, we will not be any better off.

I have been at this for many, many years. I can tell you that it is very difficult to give someone relief by using pain management medications. It has to be in the hands of the skilled or the end result will be a bigger mess.

**Mr. Roy:** It is not just a question of medication — and I know Ms Jarvis will support me on this. A great deal of pain — and I could give you a range of cases — was fundamentally caused by unrelieved emotional distress. In one case, the doctors kept giving pain control medication in higher and higher dosages. The poor patient had been abandoned by her husband. She had lost her beauty; she had lost her hair. She was bloated with steroids. She knew she would not live very long. The doctor, who understood that, came to see her day after day. He brought her small gifts, and they started to become friends. Things started to get better, and in two weeks they were able to cut down the pain control. In three weeks, she got back on her feet. This story cannot stand for all stories. When we reduce pain control to giving drugs, we are making a terrific mistake. Who has the time today to go back to see a woman or a man every day for three weeks? Doctors are cut to the bone with long waiting lists.

You can see that we are talking about a complex problem. We can change a law; however, if we do not change all these other things, the paper on which the law is written will be just a beautiful piece of paper, one that will do nothing.

**The Chairman:** I want to clarify that I do not think you are in any conflict whatsoever with either Dr. Macdonald or Dr. Mount on this particular issue.

**Senator Corbin:** Mr. Roy, I do not care to question you on anything you have said. I am quite convinced about the common sense approach to your statements and practices. I do, however, want some clarification from Ms Jarvis. You made an allusion to drug companies and a comment about leaving it in their hands. Could you expand on that, please?

**Ms Jarvis:** What I am finding in my own clinical practice is that there is very little time given to pain management and pain control in the professional work environment. What I am finding, however, is that the drug companies are providing funding for symposia, or dinner meetings, at which we discuss medications and pain control. There is nothing in my job description that specifies that I should allot any of my time to education.

**Mme Jarvis:** J'aimerais dire quelque chose au sujet de l'idée «d'abrégé la vie» et des divergences d'opinions entre les docteurs Macdonald et Mount. Le manque d'éducation ne constitue pas une bonne raison de modifier le Code criminel, parce qu'il faut avoir certaines connaissances pour pouvoir administrer ces médicaments. Si le manque d'éducation persiste, nous ne nous en retrouverons pas mieux.

Je suis dans ce domaine depuis de nombreuses années. Je peux vous dire qu'il est très difficile de soulager un patient à l'aide d'un médicament destiné à calmer la douleur. Ces médicaments doivent être administrés par quelqu'un de compétent, sinon le résultat sera pire encore.

**M. Roy:** Il ne s'agit pas simplement d'administrer des médicaments — et je sais que Mme Jarvis va confirmer ce que je dis. Bien souvent, la douleur — et je pourrais vous citer une multitude de cas — tient essentiellement à des troubles émotionnels non soulagés. Dans un cas, les médecins ne cessaient d'augmenter la dose de médicaments destinés à calmer la douleur. La pauvre patiente avait été abandonnée par son mari. Elle avait perdu sa beauté, elle avait perdu ses cheveux. Elle était gonflée par les stéroïdes. Elle savait qu'elle ne vivrait pas très longtemps. Le médecin, qui était sensible à son trouble, venait la voir tous les jours. Il lui apportait des petits cadeaux et ils sont peu à peu devenus amis. Son état a commencé à s'améliorer et, au bout de deux semaines, le médecin a pu réduire la dose d'analgésiques. Au bout de trois semaines, la patiente a pu se lever. Ce n'est là qu'un exemple parmi bien d'autres. On commet une grave erreur en pensant qu'il suffit d'administrer des médicaments pour soulager la douleur. Qui a le temps de nos jours de retourner voir un patient ou une patiente tous les jours pendant trois semaines? Les médecins sont déjà surchargés à cause des longues listes d'attente.

Comme vous pouvez le voir, le problème est complexe. On peut changer la loi, mais si on ne change pas toutes les autres choses, la loi ne sera qu'une belle mesure sur papier, qui n'aura aucun effet dans la pratique.

**La présidente:** Je voudrais bien préciser que je ne vois aucune espèce de conflit entre vous et le Dr Macdonald et le Dr Mount sur cette question.

**Le sénateur Corbin:** Monsieur Roy, je n'ai pas vraiment de question à vous poser à la suite de votre témoignage. Je suis tout à fait persuadé du bon sens de vos déclarations et de vos pratiques. Je voudrais toutefois obtenir un éclaircissement de Mme Jarvis. Vous avez fait allusion aux fabricants de médicaments et vous avez évoqué la possibilité de s'en remettre à eux. Pourriez-vous nous en dire un peu plus à ce sujet?

**Mme Jarvis:** Je constate, en tant que clinicienne, qu'on accorde très peu de temps au soulagement de la douleur dans le milieu professionnel. Je constate cependant que les fabricants de médicaments contribuent financièrement à des symposiums, ou des dîners-rencontres, où nous parlons de médicaments et de soulagement de la douleur. Il n'est pas du tout question dans ma description de poste du temps que je devrais consacrer à mon perfectionnement.



**Mr. Roy:** Ms Jarvis is correct. Drug companies have a bad name in many areas. There is the opinion out there that they give things, but at times there are really strings attached. In the area of medical research, look at the case of Dr. Olivieri in Toronto, which has turned out to be one of the worst debacles that we have had in years. The story is complex. In a good number of areas, without the drug companies we would have no education, period. In fact, we would have no seminars, symposiums or colloquiums. We would not have them, period.

If we are to get on a high horse with respect to drug-company-supported education but do not find a way ourselves to publicly that education within hospitals, clinics, long-term care units and medical schools, then we should stop criticizing the drug companies, because they are the only ones helping us in many areas to have those courses.

By and large, doctors and nurses are not stupid. They can sense when they are being pressured to push one drug over another. They are not little babies. I am not saying that that pressure is not an ethically important thing to watch out for, because it is. However, we are in a complex world. If someone asked me, "Would you prefer to have no education at all, if it cannot be funded publicly, as opposed to having education funded by drug companies with respect to palliative care and palliative medicine?" I would say, "Give me the education funded by the drug companies."

**Ms Jarvis:** That is exactly where we are right now. In nursing, for example, there is no money for education. We must approach the drug companies in order to go to conferences, or whatever. There is no money in the hospital purse for nursing education.

**Mr. Roy:** There are drug companies and then there are drug companies. There are some drug companies that have acquired the sense of societal and community mission. They are remarkable. There are also the others that can be discussed, but not here.

**Senator Corbin:** I wish to thank you very much for coming here this morning and making those statements. They are very useful and helpful.

**Senator Milne:** I am a newcomer to this committee. I am only here today, but I must tell you that your testimony before the committee this morning was most powerful and most compelling. I have concerns that arise out of it.

Dr. Roy asked: What is dying at home like? How do the poor die? Do we really want to know? Is anything being done? Are any studies being undertaken to follow through on the answers to those questions?

**M. Roy:** Mme Jarvis a raison. Les fabricants de médicaments ont mauvaise réputation dans bien des milieux. On s'imagine que leurs contributions s'accompagnent parfois de certaines conditions. Dans le domaine de la recherche médicale, il y a qu'à voir le cas du Dr Olivieri à Toronto, qui s'est révélé être un des pires fiascos que nous ayons connus depuis des années. Le cas est complexe. Dans bon nombre de domaines, il n'y aurait pas du tout d'éducation si ce n'était des fabricants de médicaments. En fait, nous n'aurions pas de séminaire, de symposium ni de colloque. Nous n'en aurions pas du tout.

Au lieu de lever le nez sur l'éducation financée par les fabricants de médicaments, il faudrait cesser de les critiquer si nous ne trouvons pas le moyen de financer publiquement cette éducation dans les hôpitaux, les cliniques, les unités de soins de longue durée et les écoles de médecine, car ils sont bien souvent les seuls à nous aider à ce chapitre.

Les médecins et les infirmiers et infirmières ne sont pas bêtes. La plupart s'en rendent compte quand on exerce des pressions sur eux pour qu'ils utilisent un médicament plutôt qu'un autre. Ce ne sont pas des enfants. Je ne dis pas qu'il n'est pas important, sur le plan éthique, d'être conscient de ces pressions, parce que c'est effectivement important. Nous vivons toutefois dans un monde complexe. Si on me demandait: «Préféreriez-vous que nous n'ayons pas du tout d'éducation, si nous n'arrivons pas à financer publiquement cette éducation, ou préférez-vous avoir une éducation dans le domaine de la médecine et des soins palliatifs qui serait financée par les fabricants de médicaments?», je dirais: «Je vais prendre l'éducation financée par les fabricants de médicaments.»

**Mme Jarvis:** C'est exactement la situation dans laquelle nous nous trouvons à l'heure actuelle. Dans le domaine des soins infirmiers, par exemple, nous n'avons pas du tout d'argent pour l'éducation. Nous devons nous adresser aux fabricants de médicaments pour pouvoir participer à des conférences ou à d'autres activités. Il n'y a pas d'argent dans les budgets des hôpitaux pour le perfectionnement du personnel infirmier.

**M. Roy:** Les fabricants de médicaments ne sont pas tous pareils. Certains d'entre eux en sont venus à penser qu'ils ont un rôle à jouer dans la société et dans la collectivité. Ils sont admirables. Il y a aussi les autres dont on pourrait parler, mais pas ici.

**Le sénateur Corbin:** Je tiens à vous remercier sincèrement d'être venus ici ce matin nous présenter ces témoignages. Ils nous seront très utiles.

**Le sénateur Milne:** Je suis nouvelle à ce comité. J'y suis pour la première fois aujourd'hui, mais je dois vous dire que les exposés que vous nous avez présentés ce matin étaient des plus convaincants et des plus éloquentes. Votre témoignage m'amène à me poser certaines questions.

Le Dr Roy a demandé: comment est-ce de mourir chez soi? Comment est-ce de mourir quand on est pauvre? Voulons-nous vraiment le savoir? Y a-t-il quelque chose qui se fait? Y a-t-il des études qui sont en cours pour essayer de trouver des réponses à ces questions?

**Mr. Roy:** With respect to the question of how the poor die, about three years ago, when I was working with some street people in the area of HIV/AIDS, I came up with an idea to organize an action research program, where the research component would be simply to get enough information to know how to model the delivery of care in the home. I devised a four-page letter of intent for a very powerful foundation in Canada. They evaluated the letter of intent, and they invited me, with other key people, to come for a personal discussion about a month ago. They rarely ever do that, which is a positive sign. At the end of April, I must deliver to them a more developed letter of intent. I am hoping that they will provide start-up money to get the studies going in several of the major cities of Canada, including rural area areas, as to how the poor die. We want to know that.

We may be surprised. The poor may die much more peacefully than the middle class and the rich; we do not know. However, I do not think they do. When we know that, we will have a much more detailed idea of how we can mobilize people like Ms Jarvis, and others, across Canada to have palliative care programs that are deliverable.

It is not clear how to do that in poor, dysfunctional families. You cannot just knock on the door and say, "Do you need some help?" Dysfunctional families are something to see. Again, there is a wide spectrum of poverty and dysfunctionality. It becomes even worse in the area of dying, when the key people in the family are going. There is the start of a movement afoot.

The international poverty health network at the WHO recently sent out an editorial that they asked all editors of nursing and medical journals to publish. I published it in the *Journal of Palliative Care*, which I have edited for the last 16 years — that is, since its beginning. We published a co-editorial on poverty, about how the poor die, and how we do not seem to have an international ethic with respect to global poverty, let alone poverty in our own countries. As the millennium changes, there seems to be the beginning of a change of social consciousness. The poverty literature is growing incredibly, not only in sociological terms but also in medical terms — that is, in ethical, broad, social-global ethical terms.

You asked: Are things happening? I think that there are the beginnings of buds that may grow into powerful activities.

**The Chairman:** I think Ms Jarvis would like to make a comment here.

**M. Roy:** Pour ce qui est de savoir comment c'est de mourir quand on est pauvre, il y a trois ans environ, quand je travaillais auprès de gens de la rue dans le domaine du VIH/sida, je me suis dit que ce serait bien de mettre sur pied un programme de recherche-action, dont le volet recherche viserait simplement à recueillir assez d'information pour savoir comment structurer la prestation de soins à domicile. J'ai rédigé une lettre d'intention de quatre pages que j'ai adressée à une très puissante fondation canadienne. Après avoir évalué ma lettre d'intention, la fondation m'a invité avec d'autres personnes clés à un entretien personnel il y a environ un mois. Il est très rare qu'on fasse une invitation semblable, ce qui augure bien. Je dois remettre à la fondation une lettre d'intention plus détaillée d'ici à la fin avril. J'espère que nous pourrions en obtenir les fonds de démarrage nécessaires pour lancer ces travaux de recherche dans plusieurs grandes villes canadiennes et aussi dans des régions rurales, sur les conditions dans lesquelles les pauvres meurent. Nous voulons savoir ce qu'il en est.

Nous serons peut-être surpris. Il se peut que les pauvres meurent dans des conditions bien plus paisibles que les gens de la classe moyenne et les riches; nous ne le savons pas. Je ne crois toutefois pas que ce soit le cas. Quand nous saurons ce qu'il en est, nous aurons une bien meilleure idée de la façon dont nous pouvons mobiliser des gens comme Mme Jarvis et d'autres, dans toutes les régions du Canada, pour mettre en place des programmes de soins palliatifs qui répondent vraiment aux besoins.

On ne sait pas trop comment assurer ces soins aux familles pauvres et dysfonctionnelles. On ne peut pas tout simplement frapper à la porte et dire: «Avez-vous besoin d'aide?» Le cas des familles dysfonctionnelles est vraiment déroutant. Il existe une grande variété dans la pauvreté et le dysfonctionnement. Les troubles sont encore plus évidents quand les membres clés de la famille sont sur le point de mourir.

On sent qu'il y a un mouvement qui s'amorce. Le réseau international des soins de santé aux pauvres à l'OMS a rédigé récemment un éditorial qu'il a envoyé à tous les rédacteurs en chef des revues destinées au personnel infirmier et aux médecins, leur demandant de le publier. Je l'ai publié dans le *Journal of Palliative Care*, dont je suis le rédacteur en chef, et ce, depuis 16 ans, c'est-à-dire, depuis sa création. Nous avons publié un co-éditorial sur la pauvreté, sur les conditions dans lesquelles les pauvres meurent et sur le fait que nous ne semblons pas avoir d'éthique internationale en ce qui concerne la pauvreté dans le monde, sans parler de la pauvreté chez nous. L'avènement du nouveau millénaire semble avoir marqué le début d'une sensibilisation à ce problème. Les ouvrages sur la pauvreté se multiplient à un rythme incroyable, et le phénomène y est abordé non seulement sur le plan sociologique, mais aussi sur le plan médical — c'est-à-dire dans l'optique d'une éthique sociale générale, voire mondiale.

Vous avez demandé s'il se passait quelque chose? Je crois qu'on voit là le germe de ce qui pourrait devenir des activités très importantes.

**La présidente:** Je crois que Mme Jarvis voudrait intervenir.



**Senator Milne:** I was just going to follow through on something Dr. Roy said, but please go ahead, Ms Jarvis.

**Ms Jarvis:** Regarding the aspects of the middle class and the poor, right here in Ottawa, in our institution, if patients do not have private insurance they cannot die at home. You must have private insurance to ensure 24-hour nursing coverage. Home care will provide up to 40 hours, which is one shift per day. There is a hidden cost in our society, in that our patients' family members often must give up their work in order to look after their loved ones at home. That is a cost that is never taken into account.

We then have the problem regarding the availability of drugs. We can often get drugs in the hospital, but when it is time for the patient to go home, their drugs are not covered by the ODB and our patients are paying out thousands of dollars a week if they choose to continue on that medication that is bringing them some relief.

**Senator Milne:** We all know which member of the family usually gives up a job to stay at home.

Dr. Roy, you spoke about this consensus towards treatment that has been developing over 20 years and how people are now backing away from it in the United States and in Canada. To try and keep this consensus going, why are there few younger people coming along to replace the aging population that you said were discovering the ethics courses and the consensual approaches? Why are there no younger replacements for them?

**Mr. Roy:** I think there are younger people coming into ethics, but I am not too sure they are coming into ethics with the same motivation to get their hands dirty emotionally; that is to say, to get into the emotional fray that you were able to find in the early people in the United States, Canada, the U.K. and, to a certain extent, in Europe. The new generation seems to be more concerned about preparing high-brow publications.

In other words, there has been a shift to the academic level in the area of clinical, medical and bioethics research. We need the academic level, but at the clinical level, physicians and nurses must have free time for that from their professional practice — for example, if you are to continue a professional practice in psychiatric nursing plus ethics of nursing, or if you are to be a physician working so many hours a week in intensive care and so many hours a week in clinical ethics. That model has not worked out very well, for economic reasons, for payment reasons.

**Le sénateur Milne:** Je voulais simplement revenir à quelque chose qu'a dit le Dr Roy, mais je vous en prie, allez-y, madame Jarvis.

**Mme Jarvis:** En ce qui concerne les différences entre la classe moyenne et les pauvres, ici même à Ottawa, dans notre établissement, les patients qui n'ont pas d'assurance ne peuvent pas mourir chez eux. Il faut avoir une assurance privée pour avoir droit à des soins infirmiers 24 heures sur 24. Les soins à domicile se limitent à 40 heures, c'est-à-dire à un relais par jour. Cette situation occasionne un coût caché pour notre société, en ce sens que les membres de la famille du patient doivent souvent quitter leur travail pour assurer à leurs êtres chers les soins à domicile dont ils ont besoin. C'est là un coût dont on ne tient jamais compte.

Nous avons aussi un problème en ce qui a trait à la disponibilité des médicaments. Il est souvent possible d'obtenir des médicaments à l'hôpital, mais quand le patient retourne chez lui, ses médicaments ne sont pas couverts par le Programme de médicaments gratuits de l'Ontario et nos patients se trouvent à payer des milliers de dollars par semaine s'ils choisissent de continuer à prendre le médicament qui soulage un peu leur douleur.

**Le sénateur Milne:** Nous savons tous quels sont les membres de la famille qui quittent généralement leur travail pour rester à la maison.

Docteur Roy, vous avez parlé de ce consensus au sujet du traitement qui se dégage depuis plus de vingt ans et du fait qu'on semble maintenant s'en éloigner aux États-Unis et au Canada. Pourquoi y a-t-il si peu de jeunes qui puissent aider à maintenir le consensus, qui puissent remplacer la population vieillissante qui, d'après ce que vous dites, découvrent la valeur des cours d'éthique et des approches consensuelles? Pourquoi n'y a-t-il pas de relève?

**M. Roy:** Je crois qu'il y a des jeunes qui s'intéressent à l'éthique, mais je ne suis pas tellement sûr qu'ils soient aussi prêts à se salir les mains sur le plan affectif, c'est-à-dire à descendre dans l'arène des émotions, comme les combattants de la première heure aux États-Unis, au Canada, au Royaume-Uni et, dans une certaine mesure, en Europe. La nouvelle génération semble plus intéressée par la rédaction de documents plus nobles, si on veut.

En d'autres termes, on semble maintenant préférer planer dans les hautes sphères de la recherche clinique, médicale et bioéthique. Nous avons besoin de ces études théoriques, mais les médecins et le personnel infirmier en pratique clinique doivent pouvoir se libérer de leur pratique professionnelle — comme l'infirmière psychiatrique qui voudrait continuer à exercer son métier mais qui devrait aussi pouvoir s'occuper de l'éthique des soins infirmiers ou comme le médecin qui voudrait continuer à travailler tant d'heures par semaine aux soins intensifs mais qui devrait aussi pouvoir passer tant d'heures par semaine à s'occuper d'éthique clinique. C'est un modèle qui, jusqu'à maintenant, n'a pas fonctionné très bien, pour des raisons économiques, pour des raisons de rémunération.



Some physicians and nurses have gone for special training in clinical ethics but they are not many in number. Those who have no medical or nursing background whatsoever and who come into the area of clinical and medical ethics are of a rare breed if they have enough science background to be become familiar with the medical and the nursing world. Instead, they tend to move into the academic area. They discuss all the same matters that we are discussing today but from a highly philosophical and academic point of view.

There are a good number who have gone into the academic world of medical and clinical ethics, but we do not have too many on the ground who are involved in the actual clinical consultation work. Then again, it is not a recognized profession. For the hundreds of consultations that I have done over 20 years, never have I accepted one cent. I was supported because I ran a research laboratory in a clinical research institute and I could take the time to do that, but mine was a rare situation.

A bioethicist who is teaching at the university is seeing more and more students per class, as the number of professors is cut back. There are many papers to grade and it is very difficult for them to leave the hill and go across the city to do a consultation on the spot.

This is a complex question with no simple answer. We must come up with some innovative ways to attract young people into this area.

**The Chairman:** As you were speaking, I was thinking of Ms Jarvis at the same time; it all seems to be part of this whole dilemma, in the academic community, between "publish or perish" or "teaching versus research" or "practice versus research" or "bedside nursing versus administrative nursing."

How can we change that direction in nursing, for example? It seems to me that the palliative care nurse is all that is left of the so-called "bedside nurse." Now we take young nursing students and we give them four or five years of training at an academic institution. Then we tell them it is not really their job to do bedside nursing, that their job is to do administrative nursing. How can we change that direction? Should we be changing that direction?

**Ms Jarvis:** That is an important but very difficult question to answer. Nursing has changed over the years, as has our population in terms of longevity and so forth. In terms of palliative care, it is absolutely pivotal for our Canadian citizens to have nurses who are actually trained appropriately in palliative care. Working as a palliative care consultant, I require a great deal of knowledge. I would never get that at the basic level doing regular bedside nursing. I do not do bedside nursing, although I am at the bedside a lot and my family will tell you I am there far too long.

Certains médecins et certains infirmiers et infirmières ont entrepris une formation spéciale en éthique clinique, mais ils ne sont pas très nombreux. Ceux qui n'ont aucune formation en médecine ou en soins infirmiers et qui s'intéressent à l'éthique clinique et médicale sont plutôt rares, car il leur faut une formation scientifique suffisante pour pouvoir comprendre le monde de la médecine et des soins infirmiers. Ils ont plutôt tendance à s'en aller du côté théorique. Ils discutent des mêmes questions dont nous discutons ici aujourd'hui, mais d'un point de vue très philosophique et savant.

On en trouve beaucoup qui s'intéressent à l'éthique médicale et clinique dans les milieux universitaires, mais nous n'en avons pas beaucoup sur le terrain qui font du travail de consultation clinique. Ce n'est d'ailleurs pas une profession reconnue. J'ai fait des centaines de consultations au cours des 20 dernières années, mais je n'ai jamais accepté la moindre rémunération. Je n'avais pas besoin d'être rémunéré parce que je dirigeais un laboratoire de recherche dans un institut de recherche clinique et que je pouvais prendre le temps de faire ces consultations, mais mon cas était exceptionnel.

Les bioéthiciens qui enseignent à l'université voient leurs classes grossir de plus en plus au fur et à mesure qu'on réduit le nombre de professeurs. Ils ont tellement de travaux à corriger et il leur est très difficile de laisser leur poste pour se rendre à l'autre bout de la ville faire une consultation en clinique.

Il s'agit d'une question complexe à laquelle il n'y a pas de réponse simple. Nous devons trouver des moyens novateurs d'attirer les jeunes dans ce domaine.

**La présidente:** Pendant que vous parliez, je pensais à Mme Jarvis; cela me rappelle toute cette question du choix qu'on doit faire dans les milieux universitaires entre «publier ou mourir», ou du choix entre «enseigner ou faire de la recherche» ou entre «la pratique et la recherche» ou encore entre «les soins infirmiers de chevet et les soins infirmiers administratifs».

Comment pouvons-nous effectuer ce virage dans les soins infirmiers, par exemple? Il me semble que l'infirmière spécialisée dans les soins palliatifs est la seule dont on peut encore dire qu'elle est «infirmière de chevet». De nos jours, les étudiants qui entrent en soins infirmiers font quatre ou cinq ans d'études dans un établissement d'enseignement. Puis, on leur dit que leur travail, ce n'est pas vraiment de dispenser des soins de chevet, mais d'accomplir des fonctions administratives. Comment pouvons-nous changer la vapeur? Devrions-nous changer la vapeur?

**Mme Jarvis:** Il s'agit là d'une question importante mais à laquelle il est très difficile de répondre. Les soins infirmiers ont changé au fil des ans avec notamment le vieillissement de la population. Sur le plan des soins palliatifs, il est absolument essentiel pour les Canadiens d'avoir des infirmiers et infirmières qui aient reçu une bonne formation en soins palliatifs. Pour exercer mes fonctions d'expert-conseil en soins palliatifs, j'ai eu besoin d'un important bagage de connaissances. Je ne pourrais pas acquérir ces connaissances en travaillant simplement comme infirmière de chevet. Je ne dispense pas de soins de chevet, même

We must start with the universities. I sound like a broken record. I have been asking: Why can't we start a course to train people, like myself, in palliative care? Then we can train others. We can train the bedside nurses to have better skills and a better understanding of what they are doing. We are so mixed up with fancy titles and theories and so on. I think the essence of patient care is often lost at the higher levels of education in nursing.

**Mr. Roy:** We need to remember where we are temporally. We are at the end of the millennium and soon to enter a new one. Times have become excessively difficult over the last four to five years, given the side effects of the financial/economic globalization movement. Governments and health care systems worldwide have been affected by budgetary constraints and cuts. Bad judgments have been taken in a number of places, like the Province of Quebec, to give excessive early retirement to the doctors and nurses who were our most skilled. We lost thousands to the "Rochon-ization" of the system. Rochon was the minister at the time. He is not the only one to blame, but the results of that decision are horrific at the moment.

Nurses are burned out and over-burdened. In those contexts, the key words are "demoralization" and "demotivation". We cannot expect superb bedside care when new ideas are coming up that need to be organized but our people are demoralized, demotivated, burnt out, and struggling at home at the same time. Nothing is getting better; the situation is getting worse.

We will close thousands of beds across the country this summer as nurses and lab technicians go on holiday. Thousands of blood samples are lined up waiting to be tested. Patients wait four or five months for important tests and, in some cases, four to five months for radiological treatment. Some patients who are able to are going to the United States to be treated.

I know you have heard all of this, but some of your questions must be discussed in that context. That was not the context in 1990, and I hope it will not be the context three years from now, but that is the context now. Some of the responses to your questions will inevitably be pessimistic or negative or uncertain or doubtful, but there are many young and not-so-young leaders who are willing to get up and say that enough is enough. Maybe we need to publicly demand the resignation of the ministers of health. At some point, we must stand up on the barricades, and we are coming very close to that point.

**Senator Beaudoin:** Yes, you referred to the report of the Law Reform Commission. I have the greatest admiration for that

si je suis souvent au chevet de patients, beaucoup trop souvent, aux dires de ma famille.

Il faut commencer par les universités. J'ai l'air de rabâcher toujours la même chose. Je ne cesse de demander pourquoi on ne pourrait pas mettre sur pied un cours de formation pour apprendre à des gens comme moi-même à donner des soins palliatifs. Ensuite, nous pourrions former d'autres personnes. Nous pourrions former les infirmiers et infirmières de chevet à avoir de meilleures compétences et à mieux comprendre leur travail. Nous nous noyons dans des titres et des théories pompeux. Je crois qu'on perd de vue l'essence des soins aux patients aux échelons supérieurs de l'enseignement des soins infirmiers.

**M. Roy:** Nous ne devons pas oublier où nous nous situons dans le temps. Nous venons de terminer un millénaire et d'entrer dans le nouveau. Avec les répercussions de la mondialisation financière et économique, les temps sont devenus très difficiles depuis quatre ou cinq ans. Les gouvernements et les régimes de soins de santé du monde entier ont été touchés par des contraintes et des restrictions budgétaires. On a commis de nombreuses erreurs de jugement dans bien des endroits, comme au Québec, en octroyant la possibilité de prendre une retraite anticipée à des médecins et des infirmières ou infirmiers éminemment qualifiés. Nous en avons perdu des milliers à cause de la «Rochon-isation» du système. C'est Rochon qui était le ministre à l'époque. Il n'est pas le seul coupable, mais les résultats de cette décision sont épouvantables.

Les infirmiers et infirmières sont complètement épuisés et surchargés de travail. Cela se traduit par les mots clés «démoralisation» et «dé motivation». On ne peut pas s'attendre à des soins de chevet de grande classe quand on se contente de proposer de nouvelles idées, alors que le personnel est démoralisé, démotivé, épuisé et qu'il se bat avec toutes sortes de difficultés. Rien ne s'améliore, la situation ne fait qu'empirer.

Nous allons fermer des milliers de lits cet été quand les infirmiers et infirmières et les techniciens de laboratoire vont partir en vacances. Il y a un arriéré de milliers d'échantillons sanguins qui attendent d'être testés. Les patients attendent pendant quatre ou cinq mois les résultats de tests importants et, dans certains cas, quatre ou cinq mois pour un traitement radiologique. Certains d'entre eux partent se faire traiter aux États-Unis s'ils en ont les moyens.

Je sais que vous avez déjà entendu tout cela, mais il faut tenir compte de ce contexte dans vos débats. Le contexte n'était pas le même en 1990, et j'espère qu'il ne sera plus le même dans trois ans, mais c'est la réalité actuellement. Certaines des réponses à vos questions seront fatalement pessimistes ou négatives ou évasives, mais il y a beaucoup de dirigeants jeunes et moins jeunes qui sont prêts à élever la voix pour dire que cela suffit. Peut-être faudrait-il que nous exigions publiquement la démission des ministres de la Santé. À un moment donné, nous allons devoir monter sur les barricades, et ce moment approche.

**Le sénateur Beaudoin:** Vous avez parlé du rapport de la Commission de réforme du droit. J'ai une profonde admiration



commission. I knew many of the commission members, including the Chief Justice of Canada and Justice Jean-Louis Beaudoin.

Are those conclusions adequate even now? Some people have changed their views to a certain extent. I remember the Sue Rodriguez case, for example, dealing with assisted suicide, though that is not part of our concern here. Do you agree that that report from 1983 or 1984 is still valid, or should it be updated?

**Mr. Roy:** No, it is valid as it is. You may want to reflect and ask other people whether something should be added, but the five points there remain for me the guiding principles that we need today, exactly as they are. We should not change the two recommendations with respect to assisted suicide or euthanasia. The other three points cover exactly what we are discussing today, almost 20 years later.

**Senator Beaudoin:** That is the purpose of my question.

**Mr. Roy:** I would push them as they stand.

**Senator Beaudoin:** They seem to be quite right, in my opinion. The other day, we were told by some doctors that we should not legislate too much. Others say we should give effect to the five points in the law reform report. I do not have any problem with that.

However, you have answered my question; you have said very clearly that the report is still valid.

**Senator Corbin:** I think the word "conundrum" may apply to the struggle between the law and professional ethics. There is the general prescription that you should not kill; that applies to everyone, war being the exception, perhaps. I would not want to see the police, the legislator, the jury, the judges and perhaps the coroner at the bedside of dying people. In other words, I put my trust in professionalism, whether it is at the nursing level, at the medical level, or any other level within that general field.

You did touch upon the perhaps excessive temptation to legislate into every minute detail what is allowed and what is not allowed in terms of palliative care and the treatment of terminally ill persons. Would either of you have a parting comment above and beyond what you have already told us?

**Mr. Roy:** I will pick up on your word "policing". A number of years ago, the United States, in the famous *Baby Doe* case, set up what were called flying squads. The moment they would get a hot call, they would come flying in to check if babies were being adequately cared for in the intensive care units or if they were being allowed to die needlessly. It was a horrific, horrendous, only-the-Americans-can-do-it kind of mess, and it died out quickly. It was police at the bedside.

The only way we can maintain the Law Reform Commission's suggested non-criminalization of euthanasia and assisted suicide adequately is if we have enough sense to know when not to apply the law. Circumstances will bring us to the borders of conflict

pour cette commission. Je connaissais plusieurs des commissaires, notamment le juge en chef du Canada et le juge Jean-Louis Beaudoin.

Est-ce que ces conclusions sont encore valables? Certains ont modifié leur point de vue. Je me souviens par exemple de l'affaire Sue Rodriguez, une affaire d'aide au suicide, bien que ce ne soit pas notre préoccupation ici. À votre avis, ce rapport de 1983 ou 1984 est-il toujours valable ou faudrait-il le mettre à jour?

**M. Roy:** Non, il est toujours valable. Vous voulez peut-être y réfléchir et demander à d'autres personnes s'il faut y ajouter quelque chose, mais ces cinq grandes lignes fondamentales demeurent à mon avis nos principes directeurs comme ils l'étaient à l'époque. Il ne faut pas modifier les deux recommandations concernant l'aide au suicide assisté ou l'euthanasie. Les trois autres points couvrent exactement les sujets dont nous parlons aujourd'hui, pratiquement 20 ans après.

**Le sénateur Beaudoin:** C'est pour cela que je posais la question.

**M. Roy:** Je les conserverais tels quels.

**Le sénateur Beaudoin:** J'estime aussi que ces arguments sont parfaitement judicieux. L'autre jour, certains médecins nous ont dit que nous ne devrions pas légiférer autant. D'autres disent que nous devrions mettre en application les cinq points de ce rapport sur la réforme du droit. Je n'ai aucune objection à cela.

Quoi qu'il en soit, vous avez répondu à ma question; vous avez dit que ce rapport était toujours valable.

**Le sénateur Corbin:** Je crois que le conflit entre le droit et l'éthique professionnelle, c'est vraiment l'histoire du serpent qui se mord la queue. Il y a d'une part la maxime générale qui dit que l'on ne doit pas tuer; cela s'applique à tout le monde, la guerre étant peut-être l'exception à cette règle. Je n'ai pas envie de voir des policiers, des législateurs, des jurys, des juges et peut-être même le coroner au chevet des mourants. Autrement dit, je fais confiance au professionnalisme, qu'il s'agisse de celui du personnel infirmier, des médecins ou de tous les intervenants de ce domaine en général.

Vous avez parlé de la tentation peut-être exagérée de légiférer dans le détail pour préciser exactement tout ce qui est autorisé ou interdit en termes de soins palliatifs et de traitements des personnes en phase terminale. Auriez-vous un dernier commentaire à ajouter à ce que vous nous avez déjà dit?

**M. Roy:** Vous avez parlé de «faire la police». Il y a un certain nombre d'années, lors de la célèbre affaire *Baby Doe*, les États-Unis ont créé ce que l'on a appelé les équipes volantes. Dès qu'il y avait un appel d'urgence, ces équipes se précipitaient pour voir si l'on s'occupait bien des bébés dans les unités de soins intensifs ou si on les laissait mourir faute de soins. Cela a été une bourde épouvantable comme seuls les Américains peuvent en commettre, et cela n'a pas duré. En gros, ça consistait à mettre des policiers à côté des lits.

Le seul moyen de maintenir correctement la proposition de la Commission de réforme du droit visant à ne pas criminaliser l'euthanasie et l'aide au suicide, c'est d'avoir assez de bon sens pour savoir quand on ne doit pas appliquer la loi. Dans certaines



between ethics and law, circumstances where the administration of high doses of drugs will be very difficult to distinguish from euthanasia. As a famous Belgian jurist said, we should maintain the law against euthanasia, but we should know when not to apply that law or when not to apply it in all of its force. Unless we have a sensitivity for the kind of complexity that characterizes human life in these areas, we will blunder in either of several extremes. There are not just two. You put your finger on one of them, and I fully support you. I am not too worried about getting to the point where we have investigative squads and so-called ethics police at the bedside because it would not work very well and it would not last very long.

**Ms Jarvis:** I agree.

**The Chairman:** When I proposed in the Senate of Canada that we needed to do a review of our unanimous recommendations from the 1995 report, it was because I thought Canadians needed to hear again from witnesses like you. Thank you very much for your presentation this morning.

Honourable senators, the Minister of Health is not able to join us next Monday. He will be joining us at some time in the future, but we have to yet to set the time.

Our next meeting will be next Tuesday at 9:00 a.m. It will be an *in camera* meeting. We will, in fact, begin the draft. Even though we have not heard from the minister, I think it is important for us to establish the parameters of our draft report. You will be receiving materials in two separate communiqués. I have made it very clear that nothing is to go out until it is available in both official languages. One document will be ready tomorrow and will be distributed to your offices. The other document, unfortunately, will not be available until Monday, at which time it will be distributed to your offices. We will proceed with our draft on Tuesday, and you will have both sets of materials, I hope, by the close of business day on Monday.

**Senator Corbin:** I am a little worried if we get the French on Monday that we will have insufficient time before the meeting to go into it. How do you plan to proceed at that meeting?

**The Chairman:** The presentation that you will receive either later today or tomorrow will, in fact, be a draft outline of where I think we want our researchers to go. We may get, quite frankly, no further than that at our meeting on Tuesday. What you will be getting later is some background materials on recommendations that we may or may not make. I am not sure we will even get there by next Tuesday. We will keep the information flowing to you as quickly as we can, and we will make it flow in both official languages.

**Senator Beaudoin:** After we hear the Minister of Health, will there be any other witnesses?

**The Chairman:** We have finished and completed with the witnesses, other than for the Minister of Health. We can make adjustments to the text after his testimony, at the appropriate time.

The committee adjourned.

circstances, nous sommes amenés à la frontière entre l'éthique et le droit, lorsqu'il devient très difficile de faire la distinction entre l'administration de doses très fortes d'un médicament et l'euthanasie. Comme le disait un célèbre juriste belge, il faut maintenir la loi interdisant l'euthanasie, en sachant quand on ne doit pas l'appliquer ou quand on ne doit pas l'appliquer intégralement. Si nous ne sommes pas sensibilisés à la complexité qui caractérise la vie humaine dans ces circonstances, nous basculerons dans un extrême ou un autre. Il n'y en a pas que deux. Vous en avez signalé un, et je suis tout à fait d'accord avec vous. Je ne me préoccupe pas tellement de l'idée d'avoir des équipes d'enquêteurs et des soi-disant policiers chargés de faire respecter l'éthique au chevet des mourants, car cela ne marcherait pas et cela ne durerait pas bien longtemps.

**M. Jarvis:** Je suis bien d'accord.

**Le président:** Quand j'ai proposé au Sénat du Canada de revoir nos recommandations unanimes du rapport de 1995, je l'ai fait parce que je pensais que les Canadiens voulaient de nouveau écouter des témoins comme vous. Merci beaucoup pour votre intervention de ce matin.

Honorables sénateurs, le ministre de la Santé ne pourra pas venir nous rencontrer lundi prochain. Nous le verrons plus tard, à une date qui n'a pas encore été fixée.

Notre prochaine réunion est fixée à mardi prochain 9 heures. Ce sera une réunion à huis clos. Nous commencerons la rédaction. Même si nous n'avons pas de nouvelles du ministre, je pense qu'il est important de délimiter les paramètres de notre ébauche de rapport. Vous recevrez les documents dans deux communiqués distincts. J'ai dit clairement qu'il n'était pas question de sortir quoi que ce soit qui ne sera pas dans les deux langues officielles. L'un des documents sera prêt demain et vous sera distribué. L'autre ne sera pas prêt avant lundi, malheureusement, et il vous sera alors distribué. Nous commencerons notre ébauche mardi, et vous aurez, je l'espère, les deux documents en fin de journée lundi.

**Le sénateur Corbin:** Je me demande si nous aurons assez de temps pour examiner le texte français avant la réunion si nous l'avons seulement lundi. Comment pensez-vous procéder lors de cette réunion?

**La présidente:** Vous allez recevoir, plus tard aujourd'hui ou demain, l'ébauche d'un plan que nous voulons que nos attachés de recherche suivent. C'est peut-être tout ce que nous ferons à notre réunion de mardi. Plus tard, vous recevrez de la documentation de fond sur les recommandations que nous pourrions formuler ou nous abstenir de formuler. Je ne suis même pas persuadée que nous en serons rendus là mardi prochain. Nous vous transmettrons l'information le plus rapidement possible et ce, dans les deux langues officielles.

**Le sénateur Beaudoin:** Après le ministre de la Santé, entendrons-nous d'autres témoins?

**La présidente:** Nous avons terminé d'entendre des témoins, sauf le ministre de la Santé. Après son témoignage, nous pourrions apporter des modifications au texte, au moment approprié.

La séance est levée.





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WITNESSES—TÉMOINS

Virginia (Ginny) Jarvis, Palliative Care Nurse Consultant,  
Ottawa Hospital;

Dr. David Roy, Clinical Research Institute of Montreal.

Virginia (Ginny) Jarvis, infirmière-consultante en soins  
palliatifs, Hôpital d'Ottawa.

Dr David Roy, Institut de recherches cliniques de Montréal.





Second Session  
Thirty-sixth Parliament, 1999-2000

## SENATE OF CANADA

*Standing Senate Committee on Social Affairs,  
Science and Technology*

*Proceedings of the Subcommittee to*

# Update “Of Life and Death”

*Chair:*  
The Honourable SHARON CARSTAIRS

Tuesday, April 11, 2000  
Tuesday, May 9, 2000  
Monday, May 15, 2000

Issue No. 10

Deuxième session de la  
trente-sixième législature, 1999-2000

## SÉNAT DU CANADA

*Comité sénatorial permanent des affaires sociales,  
des sciences et de la technologie*

*Délibérations du sous-comité de*

# Mise à jour de «De la vie et de la mort»

*Présidente:*  
L'honorable SHARON CARSTAIRS

Le mardi 11 avril 2000  
Le mardi 9 mai 2000  
Le lundi 15 mai 2000

Fascicule n° 10

### **Tenth, Eleventh and Twelfth meetings on:**

Examination of the developments since the tabling in  
June 1995 of the final report of the Special Senate  
Committee on Euthanasia and Assisted Suicide,  
entitled: “Of Life and Death”

APPEARING:  
The Honourable Allan Rock, P.C., M.P.,  
Minister of Health

WITNESSES:  
(See back cover)

**Dixième, onzième et douzième réunions concernant:**  
L'étude des faits nouveaux survenus depuis le dépôt,  
en juin 1995, du rapport final du comité sénatorial  
spécial sur l'euthanasie et l'aide au suicide intitulé:  
«De la vie et de la mort»

COMPARAIT:  
L'honorable Allan Rock, c.p., député,  
ministre de la Santé

TÉMOINS:  
(Voir à l'endos)

THE SUBCOMMITTEE TO UPDATE  
“OF LIFE AND DEATH”

The Honourable Sharon Carstairs, *Chair*

The Honourable Gérald-A. Beaudoin, *Deputy Chair*

and

The Honourable Senators:

\* Boudreau, P.C.  
(or Hays)  
Corbin  
Keon

\* Lynch-Staunton  
(or Kinsella)  
Pépin

\* *Ex Officio Members*

(Quorum 3)

*Changes in membership of the committee:*

Pursuant to rule 85(4), membership of the committee was amended as follows:

The name of the Honourable Senator Pépin was substituted for that of the Honourable Senator Milne (*May 8, 2000*).

The name of the Honourable Senator Corbin was substituted for that of the Honourable Senator Kirby (*April 10, 2000*).

The name of the Honourable Senator Milne was substituted for that of the Honourable Senator Pépin (*April 10, 2000*).

The name of the Honourable Senator Pépin was substituted for that of the Honourable Senator Milne (*April 5, 2000*).

The name of the Honourable Senator Kirby was substituted for that of the Honourable Senator Corbin (*April 5, 2000*).

LE SOUS-COMITÉ DE MISE À JOUR DE  
«DE LA VIE ET DE LA MORT»

*Présidente:* L'honorable Sharon Carstairs

*Vice-président:* L'honorable Gérald-A. Beaudoin

et

Les honorables sénateurs:

\* Boudreau, c.p.  
(ou Hays)  
Corbin  
Keon

\* Lynch-Staunton  
(ou Kinsella)  
Pépin

\* *Membres d'office*

(Quorum 3)

*Modifications de la composition du comité:*

Conformément à l'article 85(4) du Règlement, la liste des membres du comité est modifiée, ainsi qu'il suit:

Le nom de l'honorable sénateur Pépin est substitué à celui de l'honorable sénateur Milne (*le 8 mai 2000*).

Le nom de l'honorable sénateur Corbin est substitué à celui de l'honorable sénateur Kirby (*le 10 avril 2000*).

Le nom de l'honorable sénateur Milne est substitué à celui de l'honorable sénateur Pépin (*le 10 avril 2000*).

Le nom de l'honorable sénateur Pépin est substitué à celui de l'honorable sénateur Milne (*le 5 avril 2000*).

Le nom de l'honorable sénateur Kirby est substitué à celui de l'honorable sénateur Corbin (*le 5 avril 2000*).

**MINUTES OF PROCEEDINGS**

OTTAWA, Tuesday, April 11, 2000

(12)

[English]

The Subcommittee to update "Of Life and Death" met this day *in camera* in room 257, East Block, at 9:06 a.m., the Honourable Sharon Carstairs, Chair, presiding.

*Members of the subcommittee present:* The Honourable Senators Beaudoin, Carstairs and Corbin (3).

*Other senator present:* The Honourable Senator Roche (1).

*In attendance:* Nancy Miller-Chénier, Research Officer, Research Branch, Library of Parliament.

The subcommittee proceeded to consider a draft outline of a report.

At 10:45 a.m., the subcommittee adjourned to the call of the Chair.

ATTEST:

OTTAWA, Tuesday, May 9, 2000

(13)

[English]

The Subcommittee to update "Of Life and Death" met this day *in camera* in room 257, East Block, at 9:03 a.m., the Honourable Sharon Carstairs, Chair, presiding.

*Members of the subcommittee present:* The Honourable Senators Beaudoin, Carstairs, Corbin, Keon and Pépin (5).

*Other senator present:* The Honourable Senator Roche (1).

*In attendance:* Nancy Miller-Chénier and Mollie Dunsmuir, Research Officers, Research Branch, Library of Parliament.

The subcommittee proceeded to consider a draft outline of a report.

At 11:16 a.m., the subcommittee adjourned to the call of the Chair.

ATTEST:

OTTAWA, Monday, May 15, 2000

(14)

[English]

The Subcommittee to update "Of Life and Death" met this day *in camera* in room 257, East Block, at 2:08 p.m., the Honourable Sharon Carstairs, Chair, presiding.

**PROCÈS-VERBAUX**

OTTAWA, le mardi 11 avril 2000

(12)

[Traduction]

Le sous-comité de la mise à jour de «De la vie et de la mort» se réunit à huis clos aujourd'hui, à 9 h 06, dans la pièce 257 de l'édifice de l'Est, sous la présidence de l'honorable sénateur Sharon Carstairs (*présidente*).

*Membres du comité présents:* Les honorables sénateurs Beaudoin, Carstairs et Corbin (3).

*Autre sénateur présent:* L'honorable sénateur Roche (1).

*Également présente:* Nancy Miller-Chénier, attachée de recherche, Direction de la recherche parlementaire, Bibliothèque du Parlement.

Le sous-comité examine l'ébauche du rapport.

À 10 h 45, le sous-comité suspend ses travaux jusqu'à nouvelle convocation de la présidence.

ATTESTÉ:

OTTAWA, le mardi 9 mai 2000

(13)

[Traduction]

Le sous-comité de la mise à jour de «De la vie et de la mort» se réunit à huis clos aujourd'hui, à 9 h 03, dans la pièce 257 de l'édifice de l'Est, sous la présidence de l'honorable sénateur Sharon Carstairs (*présidente*).

*Membres du comité présents:* Les honorables sénateurs Beaudoin, Carstairs, Corbin, Keon et Pépin (5).

*Autre sénateur présent:* L'honorable sénateur Roche (1).

*Également présente:* Nancy Miller-Chénier, attachée de recherche, Direction de la recherche parlementaire, Bibliothèque du Parlement.

Le sous-comité examine l'ébauche du rapport.

À 11 h 16, le sous-comité suspend ses travaux jusqu'à nouvelle convocation de la présidence.

ATTESTÉ:

OTTAWA, le lundi 15 mai 2000

(14)

[Traduction]

Le sous-comité de la mise à jour de «De la vie et de la mort» se réunit à huis clos aujourd'hui, à 14 h 08, dans la pièce 257 de l'édifice de l'Est, sous la présidence de l'honorable sénateur Sharon Carstairs (*présidente*).



*Members of the subcommittee present:* The Honourable Senators Beaudoin, Carstairs and Corbin (3).

*Other senator present:* The Honourable Senator Roche (1).

*In attendance:* Nancy Miller-Chénier and Mollie Dunsmuir, Research Officers, Research Branch, Library of Parliament.

The subcommittee proceeded to consider a draft report.

At 3:22 p.m., the subcommittee suspended.

At 3:30 p.m., the subcommittee resumed and proceeded in public to its examination of the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death". (*For full text of Order of Reference please refer to Issue No. 1.*)

**APPEARING:**

The Honourable Allan Rock, P.C., M.P., Minister of Health.

**WITNESSES:**

*From the Department of Health Canada:*

Cliff Halliwell, Director General, Applied Research and Analysis Directorate, Information, Analysis and Connectivity Branch;

Barbara Ouellet, Director of Home Care and Pharmaceuticals, Health Care Directorate, Policy and Consultation Branch;

Dr. Christina Mills, Director, Cancer Bureau, Laboratory Centre for Disease Control, Health Protection Branch.

The Chair made an opening statement.

The Honourable Allan Rock made a statement and, together with Cliff Halliwell and Barbara Ouellet, answered questions.

At 4:31 p.m., the subcommittee resumed *in camera*.

At 4:34 p.m., the subcommittee adjourned to the call of the Chair.

**ATTEST:**

*Membres du comité présents:* Les honorables sénateurs Beaudoin, Carstairs et Corbin (3).

*Autre sénateur présent:* L'honorable sénateur Roche (1).

*Également présente:* Nancy Miller-Chénier, attachée de recherche, Direction de la recherche parlementaire, Bibliothèque du Parlement.

Le sous-comité examine l'ébauche du rapport.

À 15 h 22, le sous-comité suspend ses travaux.

À 15 h 30, le sous-comité reprend ses travaux en public pour étudier les faits nouveaux survenus depuis le dépôt, en juin 1995, du rapport final du comité spécial du Sénat sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort». (*Voir le texte complet de l'ordre de renvoi dans le fascicule numéro 1.*)

**COMPARAÎT:**

L'honorable Allan Rock, c.p., député, ministre de la Santé.

**TÉMOINS:**

*Du ministère de la Santé:*

Cliff Halliwell, directeur général, Direction de la recherche appliquée et de l'analyse, Direction générale de l'information, de l'analyse et de la connectivité;

Barbara Ouellet, directrice, Direction des soins à domicile et des produits pharmaceutiques, Direction générale des politiques et de la consultation;

Dre Christina Mills, directrice, Bureau du cancer, Laboratoire de lutte contre la maladie, Direction générale de la protection de la santé.

La présidente fait une déclaration.

L'honorable Allan Rock fait une déclaration et, avec Cliff Halliwell et Barbara Ouellet, répond aux questions.

À 16 h 31, le sous-comité poursuit ses travaux à huis clos.

À 16 h 34, le sous-comité suspend ses travaux jusqu'à nouvelle convocation de la présidence.

**ATTESTÉ:**

*La greffière du sous-comité,*

Heather Lank

*Clerk of the Subcommittee*

## EVIDENCE

OTTAWA, Monday, May 15, 2000

The Subcommittee to Update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology met this day at 3:30 p.m. to examine the developments since the tabling in June 1995 of the final report of the Special Senate Committee on Euthanasia and Assisted Suicide, entitled "Of Life and Death."

**Senator Sharon Carstairs** (*Chairman*) in the Chair.

[*English*]

**The Chairman:** Honourable senators, I wish to welcome to our table this afternoon the Honourable Allan Rock, Minister of Health. He is accompanied today by Dr. Christina Mills, Cliff Halliwell, and Barbara Ouellet.

We welcome you all. I understand that the minister will begin with some opening remarks; and then, if we ask questions for which he does not have the detailed answers, we will allow him to turn to the other witnesses.

**Hon. Allan Rock, Minister of Health:** Madam Chairman, honourable senators, thank you very much. I want to say how delighted I am to have this chance to appear before you today.

[*Translation*]

You considered at some length the issue of palliative care in the health care system. Today, I am pleased to report on Health Canada's efforts to weigh and respond to the needs of Canada's health care system in terms of palliative care.

[*English*]

I should say first that some years ago, when you produced your report, I was extremely impressed by its depth and the sensitivity of its analysis. At that time I was in a different portfolio, but I remember welcoming your recommendations on palliative care. Although it was difficult for the committee to find consensus on some of the other issues, certainly in relation to palliative care, there was broad support for your recommendations about Canada-wide discussions on standards and approaches. They struck me as extremely sensible. Also, at the very beginning, I will say that, as I look back over the years since your report, I think there is much more that remains to be done. I wish that I could come before you today and say that we have done everything you recommended and that we have made as much progress as you thought possible when you reported, but we have not. I will refer to some of the things that we have done, but I want to be frank with you and say that there is much left outstanding.

I do not pretend for a minute that we have complied with all of your recommendations or achieved everything that you had in mind when you reported. There is a lot more that has to be done.

## TÉMOIGNAGES

OTTAWA, le lundi 15 mai 2000

Le sous-comité de mise à jour de «De la vie et de la mort» du comité sénatorial permanent des affaires sociales, des sciences et de la technologie se réunit aujourd'hui à 15 h 30 pour examiner les faits survenus depuis le dépôt, en juin 1995, du rapport final du comité sénatorial spécial sur l'euthanasie et l'aide au suicide intitulé: «De la vie et de la mort».

**Le sénateur Sharon Carstairs** (*présidente*) occupe le fauteuil.

[*Traduction*]

**La présidente:** Honorables sénateurs, je souhaite la bienvenue à notre table, cet après-midi, à l'honorable Allan Rock, ministre de la Santé. Il est accompagné aujourd'hui de Mme Christina Mills, de Cliff Halliwell et de Barbara Ouellet.

Nous vous souhaitons la bienvenue à tous. Si j'ai bien compris, le ministre présentera les observations préliminaires; ensuite, si nous posons des questions auxquelles il ne peut donner de réponse détaillée, nous lui permettrons de céder la parole à d'autres témoins.

**L'honorable Allan Rock, ministre de la Santé:** Madame la présidente, honorables sénateurs, je vous remercie beaucoup. Je tiens à vous dire combien il me fait plaisir d'avoir cette opportunité de témoigner devant vous aujourd'hui.

[*Français*]

Vous avez longuement étudié la question des soins palliatifs dans le système des soins de santé. Aujourd'hui, je suis heureux de décrire ce que nous avons fait à Santé Canada pour considérer et réagir aux besoins du système de santé canadien à l'égard des soins palliatifs.

[*Traduction*]

Je dois dire qu'il y a quelques années, lorsque vous avez présenté votre rapport, j'ai été très impressionné par la profondeur et la sensibilité de l'analyse qui y était faite. Je tenais un autre portefeuille à l'époque, mais je me rappelle avoir reconnu le bien fondé de vos recommandations sur les soins palliatifs. Même s'il a été difficile pour le comité d'arriver à un consensus sur d'autres sujets, en ce qui concerne les soins palliatifs, vos recommandations en vue de la tenue dans tout le Canada de discussions sur les normes et les procédés ont reçu un appui généralisé. Ces recommandations m'ont paru particulièrement sensées. De plus, avant d'aller plus loin, j'aimerais dire qu'à l'examen des faits survenu depuis le dépôt de votre rapport il y a quelques années, je constate qu'il reste encore beaucoup à faire. J'aurais aimé pouvoir dire devant vous aujourd'hui que nous avons mis à exécution toutes vos recommandations et que nous avons réalisé tous les progrès que vous pensiez possibles au moment de votre rapport, mais ce n'est pas le cas. Je vais parler de certaines choses qui ont été faites, mais je tiens à être franc avec vous en vous disant qu'il reste encore beaucoup à faire.

Je ne prétendrai pas un seul instant que nous nous sommes pliés à toutes vos recommandations ou que nous avons réalisé tout ce que vous aviez envisagé au moment de votre rapport. Il reste encore beaucoup de pain sur la planche.



I think that part of the reason for that is that the whole health care system is in a period of transition. Twenty-five years ago, almost half of health spending in Canada took place in hospitals. Now it is less than one-third. Much of health care has moved outside the institution and into the community, but the Canada Health Act only insures services that take place in the hospital and are provided by doctors. Therefore, public coverage has not expanded to catch up with the disbursement of the services. The whole area of home and community care has, therefore, been calling out for more attention. Of course, provincial governments are responding, each in its own way, and some of them are doing a wonderful job. However, it is an uneven response across the country, and that is why, as we meet with provincial governments to talk about renewing the health care system, care outside the hospital is an important subject.

Care outside the hospital has particular significance for the subject that I am speaking about today, which is palliative care. Typically, we are talking about the hospice or the home or some non-hospital setting where the end of life occurs and where palliative care is delivered. I for one see home and community care as part of a continuum, with palliative care being one end of that. There is still a lot to do, but I think we are in the process of looking at, with the provinces, the renewal of medicare. We will have to bear in mind, as we do that, the extent to which care is provided outside the hospital and that palliative care is an important part of that overall scheme.

*[Translation]*

At this time, I will briefly review for your benefit the department's efforts to comply with your recommendations. Mention should be made of the health services restructuring fund. Three years ago, we established a \$150 million fund to enable the provinces to carry out pilot projects in four areas, including community care, home care and palliative care.

Pilot projects on palliative care in rural areas were funded in Nova Scotia and Prince Edward Island. Our department helped finance pilot projects in Quebec, working in cooperation with the CLSCs. The projects involved training palliative care workers.

We expect the results of these pilot projects to be available within the next few months. Once the evaluation process is completed, a report will be produced with a view to drawing the provinces' attention to the important lessons to be learned from these different experiences. This is the primary objective of the health services restructuring fund.

The aim of the pilot projects is to test different approaches, to get an idea of the best practices and to enable the provinces to publish results and adopt effective courses of action.

Je crois que c'est en partie attribuable au fait que l'intégralité du régime de soins de santé vit une période de transition. Il y a 25 ans, près de la moitié des coûts des soins de santé étaient assumés par les hôpitaux. De nos jours, c'est moins d'un tiers. Une bonne part des soins de santé ne sont plus donnés en milieu hospitalier mais dans la communauté, alors que la Loi canadienne sur la santé n'assure que les services qui sont donnés dans les hôpitaux et administrés par des médecins. Par conséquent, la protection du public n'a pas été adaptée de manière à couvrir les frais des services. C'est pourquoi tout le secteur des soins de santé au foyer et dans la communauté réclame plus d'attention depuis quelque temps. Il est certain que les gouvernements provinciaux réagissent, chacun à sa manière, et quelques-uns avec beaucoup de succès. Cependant, les mesures de réaction sont inégales dans tout le pays et c'est pourquoi, alors que nous rencontrons les gouvernements provinciaux pour parler du renouvellement du système de soins de santé, la question des soins en dehors des hôpitaux revêt une grande importance.

Cette question a une importance particulière en rapport à l'objet de ma présence ici aujourd'hui, c'est-à-dire les soins palliatifs. Généralement, les soins palliatifs sont les soins donnés à l'hospice, ou au domicile, ou dans quelque milieu non hospitalier où prend fin la vie. Pour moi, les soins à domicile et dans la communauté font partie intégrante d'un continuum dont les soins palliatifs constituent l'extrémité. Il y a encore beaucoup à faire, mais je pense que nous avons entamé, avec les provinces, l'examen du renouvellement du régime de santé. En faisant cet examen, nous devons garder à l'esprit la mesure dans laquelle les soins sont administrés hors de l'hôpital et le fait que les soins palliatifs sont une part importante du tableau d'ensemble.

*[Français]*

Permettez-moi de décrire brièvement les efforts que le ministère a déployés pour respecter vos recommandations. Par exemple, mentionnons le fonds pour la restructuration des services de santé. Il y a trois ans nous avons créé un fonds de 150 millions de dollars permettant aux provinces de mener des projets pilotes dans quatre catégories, dont les soins communautaires, y compris les soins à domicile et les soins palliatifs.

Des projets pilotes portant sur les soins palliatifs dans le contexte rural ont été financés en Nouvelle-Écosse et à l'Île-du-Prince-Édouard. Au Québec, nous avons financé des projets pilotes en collaboration avec les CLSC. Ces projets visaient la formation et l'entraînement des gens dans le domaine des soins palliatifs.

Nous nous attendons à ce que les résultats de ces projets pilotes soient disponibles d'ici quelques mois. Une fois les projets pilotes terminés et évalués, un rapport sera publié afin d'attirer l'attention des provinces sur les leçons importantes à tirer de ces différentes expériences. C'est l'objectif primordial du fonds pour la restructuration des services de santé.

Les projets pilotes ont pour but d'essayer des approches différentes, de tirer des leçons quant aux meilleures pratiques, et permettent aux provinces de publier les résultats et de mettre en place des approches qui fonctionnent bien.



You made it clear in your report and recommendations that the federal government has a special responsibility to assume in the field of health research.

You are no doubt aware that with the passage of Bill C-13, the federal government launched the Canadian Institutes of Health Research initiative. Several institutes will be up and running in a few weeks' time and the Prime Minister will be announcing the members of the boards of directors.

In addition, we have doubled the health research budget, which now totals \$500 million a year. I am confident that an institute dealing with palliative care will be on the list of announcements by the board of directors. I know that research into this particular field will increase. As a result of additional funding, the establishment of institutes and increased research, we will gain a better understanding of the needs of Canada's health care system in the years to come.

[English]

Briefly, a list of infrastructure investments by the Government of Canada: tele-medicine, which has been adapted to tele-hospice services; aboriginal health, where we have devoted \$90 million a year, commencing in 2003-2004, for home and community care in First Nations communities, including end-of-life care; and the work we have done in respect of HIV/AIDS. I think that all of these have been helpful and responsive to your recommendations in a general way.

I will close as I began, by saying that there is much more left to do and I do not pretend that we have fulfilled your recommendations to their fullest in the years since you published your report. We acknowledge the need for more attention, and that, particularly with the aging of our population, there is more work to be done, and we will do it. I am grateful for this chance to engage in a dialogue with the committee and I look forward to any comments and questions that you may have.

**Senator Beaudoin:** It has been a great experience to be a member of the subcommittee regarding those questions. We have, of course, focused on those issues on which we were unanimous, so it settles most of the legal questions.

[Translation]

Much has been said about refusing treatment and withdrawing measures. When it comes to palliative care, the law is very clear. For the most part, this comes under provincial jurisdiction. Federal legislation is in place covering the unplugging of machines and the refusal of treatment, but perhaps it needs to be more specific. Mr. Minister, would it not be better to have somewhat clearer legislation governing this field so that we are not always waiting to see how the courts react? I think we should take the initiative and set about addressing these issues.

Dans votre rapport et vos recommandations, vous avez souligné que le gouvernement fédéral a une responsabilité particulière concernant la recherche en santé.

Vous savez probablement que nous avons lancé les instituts de recherche en santé du Canada. Nous avons adopté le projet de loi C-13, le projet de loi visant à créer les instituts. D'ici quelques semaines les instituts seront en fonction et le premier ministre présentera les membres du conseil d'administration.

De plus, nous avons doublé le budget pour la recherche en santé, budget s'élevant à 500 millions de dollars par année. Je suis convaincu que parmi les instituts que le conseil d'administration va nommer ou identifier, on trouvera un institut traitant de soins palliatifs. Je suis certain que la recherche dans ce domaine sera intensifiée. Avec les fonds additionnels, la création d'instituts et la recherche intensifiée, nous aurons dans les années qui viennent une meilleure compréhension des besoins du système de santé au Canada.

[Traduction]

Je vais vous donner brièvement la liste des investissements qu'a faits le gouvernement du Canada dans l'infrastructure: la télémédecine, qui a été adaptée aux services de télé-hospice: la santé des autochtones, à laquelle nous avons réservé 90 millions de dollars par année au budget, à partir de 2003-2004, au titre des soins au foyer et dans les collectivités des Premières nations, y compris les soins aux patients en phase terminale; et les travaux que nous avons faits relativement au VIH et au sida. Je pense que chacun de ces éléments a été utile et répondait à vos recommandations de façon générale.

Je terminerai comme j'ai commencé, en disant qu'il reste encore beaucoup à faire et que je n'oserais pas prétendre que nous avons tout à fait suivi vos recommandations depuis la publication de votre rapport. Nous reconnaissons la nécessité de porter plus d'attention au sujet et que, particulièrement en raison du vieillissement de la population, il y a encore beaucoup à faire, et nous le ferons. Je suis reconnaissante au comité de cette occasion qui m'est donnée de dialoguer avec lui et j'accueillerai avec plaisir vos observations et vos questions.

**Le sénateur Beaudoin:** Il a été très enrichissant de siéger à ce sous-comité et d'y traiter de ces questions. Nous nous sommes, c'est certain, concentrés sur les questions qui faisaient l'unanimité, ce qui règle la plupart des questions d'ordre juridique.

[Français]

Nous avons beaucoup parlé de refus de traitement et du «withdrawal of instruments». La jurisprudence est très claire en ce qui a trait aux soins palliatifs, c'est en bonne partie de juridiction provinciale. Nous avons une législation fédérale pour les débranchements d'appareils et les refus de traitement, mais peut-être devrait-elle être plus précise. Monsieur le ministre, croyez-vous qu'il serait avantageux d'avoir des lois un peu plus claires dans ce domaine afin que nous ne soyons pas à la remorque des tribunaux? Nous devrions prendre l'initiative de régler ces problèmes.

I do not wish to get into a discussion as to what areas come under provincial or federal jurisdiction. However, provincial jurisdiction over palliative care services must be respected. There are certain steps that you could take. As Health Minister, you oversee the enforcement of the Canada Health Act. Should this legislation remain in its present form or should it be improved upon, given the circumstances?

**Mr. Rock:** I do not care to comment on that. However, as Minister of Health, my concern is the accessibility of health care services. As I said, palliative care is part of community care and home care services. Palliative care is provided in a hospital setting, as well as out in the community.

**Senator Beaudoin:** At home?

**Mr. Rock:** Yes, at home, or in hospices or at other locations within the community. We are currently discussing with the provinces the initiatives that could be taken as part of a government partnership to renew and strengthen our health care system. Community care is one area being discussed. The important thing to ensure is that all people in all parts of Canada have access to quality services.

Palliative care is one such essential service. I intend to work with my counterparts to ensure that these objectives are met.

**Senator Beaudoin:** Will these objectives in fact be met as a result of the federal spending power or through the normal collaborative effort between Ottawa and the provinces?

**Mr. Rock:** Cooperation is always critical in the field of health care.

**Senator Beaudoin:** That is the problem. However, there is a way of cooperating. The provinces always want more and the federal government is prepared to spend more on health care. Could some kind of agreement possibly be reached?

**Mr. Rock:** Possibly. A few months ago, I wrote to the provincial health ministers and invited them to sit down at the table with us to discuss ways of working together to improve the system. I met with my provincial counterparts a few weeks ago in Markham where they requested additional funding, to which I responded that we also need an integrated plan. We are now in the process of working on such a plan.

**Senator Beaudoin:** I concur with this approach.

[English]

**Senator Corbin:** I do not want to misrepresent the minister's statement, but in commenting on our 1995 report, did he say that much more could have been done?

Certainly a lot more has to be done, but speaking for myself, and the sentiment may be shared by some of my colleagues, we feel that your department could have done much more in terms of our specific recommendations. There may be a reason why more was not done. Is it a jurisdictional problem?

Je n'entre pas dans ce qui est sous la juridiction provinciale ou fédérale. Cependant, la juridiction des provinces en matière de soins palliatifs doit, bien sûr, être respectée. Il y a des moyens pour le faire. En tant que ministre de la Santé, vous voyez à l'application de la Loi sur la santé. Cette loi doit-elle demeurer exactement comme elle l'est actuellement ou doit-on l'améliorer, étant donné le contexte?

**M. Rock:** Je n'ai aucune opinion là-dessus, mais comme ministre de la Santé, ma préoccupation est l'accessibilité aux services de soins de santé. Comme je l'ai dit, les soins palliatifs font partie des soins communautaires, des soins à domicile. Les soins palliatifs sont pertinents dans les hôpitaux, mais également à l'extérieur de ceux-ci.

**Le sénateur Beaudoin:** À domicile?

**M. Rock:** Oui, à domicile ou dans les hospices ou d'autres endroits dans les communautés. Nous sommes en train de discuter avec les provinces au sujet de ce que nous pouvons faire dans un partenariat gouvernemental pour renouveler et renforcer notre système de soins de santé. Les soins communautaires font partie de ces discussions. Il est important de faire en sorte qu'on ait accès aux services de qualité pour tout le monde, partout au Canada.

Les soins palliatifs font partie de ces services essentiels. C'est ma préoccupation et je vais travailler avec mes homologues pour faire en sorte que ces objectifs soient atteints.

**Le sénateur Beaudoin:** Est-ce grâce au pouvoir fédéral de dépenser ou est-ce grâce à la collaboration normale entre Ottawa et les provinces?

**M. Rock:** La collaboration est toujours importante dans le domaine de la santé.

**Le sénateur Beaudoin:** C'est la seule difficulté, mais il y a toujours moyen de collaborer. Les provinces veulent toujours en avoir davantage et le gouvernement fédéral est prêt à dépenser davantage dans le domaine de la santé, mais est-ce possible dans un protocole d'entente?

**M. Rock:** On verra. J'ai invité mes homologues à se joindre à nous à la table. J'ai écrit, il y a quelques mois, aux ministres de la santé provinciaux. Je les ai invités pour discuter davantage des moyens de travailler ensemble afin de renforcer le système. Nous avons tenu une réunion à Markham il y a quelques semaines. Ils ont demandé plus de fonds. J'ai répondu qu'on avait besoin également d'un plan intégré. Nous y travaillons actuellement.

**Le sénateur Beaudoin:** Je suis d'accord avec cette approche.

[Traduction]

**Le sénateur Corbin:** Je ne voudrais pas mal interpréter la déclaration du ministre, mais a-t-il dit, lorsqu'il parlait de notre rapport de 1995, que beaucoup plus aurait pu être fait?

C'est certain que beaucoup plus aurait pu être fait, mais pour mon compte, et je pense que certains de mes collègues partagent mon opinion, il me semble que votre ministère aurait pu faire beaucoup plus en ce qui concerne nos recommandations spécifiques. Peut-être y a-t-il une raison qui explique pourquoi il



You have given us examples of ongoing programs that I am sure will make it possible to resolve some of the issues and challenges, but why was more not done in the intervening five years? Is it because of the continuing hassle between the federal and provincial governments in the field of health?

Surely it cannot be simply a money matter, because even in dire circumstances one still has to look after the sick and dying, but usually one implements the latest science, the latest technology. One reallocates one's resources to the people who need help most. I would suggest that surely dying people, leaving aside disease control and that sort of thing, are the ones who are in greatest need.

We must still repeat many of our 1995 recommendations in the hope that, now that you are Minister of Health — you spoke to us previously in your capacity as Minister of Justice — you can tell us what you think can be accomplished in the next five years on this front.

We will all die, Mr. Minister. Most of us, unless we drop dead on the street because of a ruptured artery in the brain, will go through some excruciating pain and extended illness. Surely that is one of the great challenges right now in the minds of many Canadians, the provision of the best possible palliative care services.

**Mr. Rock:** It was in late 1994 and early 1995 that I learned those lessons for myself. One after the other, my mother and then my father died, each of them of cancer and each of them at home. My sisters and I discovered for ourselves how difficult it was to find out what home care services were available, which ones were paid for by public insurance, which ones we had to pay for out of pocket, and which were available through private insurance.

We also found out that palliative care in the end stages of cancer — and most palliative care arises in the context of cancer — requires much attention and presents some difficult questions.

The easy answer to your question, senator, is that the actual organization and delivery of services is a provincial responsibility. Do not grimace.

**Senator Corbin:** I shrug.

**Mr. Rock:** Do not shrug either, with respect, because whenever I talk about my ambitions for improving the health care system, the first people to tell me to sit down and shut up are the provincial officials, ministers and premiers, who say, "That is our problem. Do not get into your boutique programs and do not tell us what to do. Mind your own business and just send the money."

n'y en a pas plus qui a été fait. Y a-t-il un problème de juridiction?

Vous nous avez cité des exemples de programmes en cours qui, j'en suis sûr, permettront de vaincre certains obstacles et difficultés, mais pourquoi n'en a-t-on pas plus fait dans l'intervalle de ces cinq ans? Est-ce que c'est à cause des tiraillements constants entre le gouvernement fédéral et ceux des provinces à propos de la santé?

Ce ne peut tout de même pas être une simple question d'argent, parce que même dans les pires situations, il faut encore s'occuper des malades et des mourants, mais normalement on applique les progrès scientifiques et technologiques les plus récents. On répartit les ressources entre ceux qui en ont le plus besoin. À mon avis, mis à part les questions de lutte contre la maladie et ce genre de choses, les mourants sont ceux qui ont les plus grands besoins.

Nous devons encore répéter la plupart de nos recommandations faites en 1995 dans l'espoir que, maintenant que vous voilà ministre de la Santé — vous aviez déjà comparu devant nous à titre de ministre de la Justice — vous pouvez nous dire ce qui, à votre avis, peut être fait dans les cinq prochaines années sur ce plan.

Nous mourrons tous un jour, monsieur le ministre. La plupart d'entre nous, à moins de nous écrouler dans la rue victimes de la rupture d'une artère dans le cerveau, connaîtront une douleur intolérable et une longue maladie. Je ne doute pas que ce soit une des grandes préoccupations de bon nombre de Canadiens actuellement, la prestation de soins palliatifs de la meilleure qualité possible.

**M. Rock:** J'ai moi-même vécu ce genre de situation de près à la fin de 1994 et au début de 1995. L'un à la suite de l'autre, ma mère, puis mon père sont morts du cancer, à la maison. Mes soeurs et moi avons vite constaté combien il était difficile de savoir quel genre de services de soins à domicile étaient disponibles, lesquels étaient défrayés par les assurances publiques, lesquels nous devions payer de notre propre poche et lesquels étaient prévus par les régimes d'assurance privés.

Nous avons aussi découvert que les soins palliatifs en phase terminale du cancer — et la plupart des soins palliatifs doivent être administrés dans ce contexte — nécessitent beaucoup d'attention et soulèvent des questions très difficiles.

La réponse la plus simple à votre question, sénateur, est que l'organisation et la prestation elles-mêmes des services relèvent des provinces. Ne faites pas la grimace.

**Le sénateur Corbin:** Je n'ai fait que hausser les épaules

**M. Rock:** Alors ne haussez pas non plus les épaules, avec tout le respect que je vous dois, parce que chaque fois que je parle de mes vœux d'amélioration du système de soins de santé, les premiers à me dire de prendre mon trou et de me taire sont les hauts représentants des provinces, les ministres et les premiers ministres qui décrètent: «c'est notre problème. Ne nous parlez pas de vos programmes de points de service et ne nous dites pas quoi faire. Mêlez-vous de vos affaires et contentez-vous de nous envoyer l'argent».



We have to deal with that reality every day. I say that not because I am trying to evade your question, but because I am trying to answer it in part. Part of the reality is that it is the provinces that organize and deliver care. That is the way the Constitution is written and the way the country works.

Does the Government of Canada have a role to play? Absolutely. What is that proper role? The very things that you have recommended — national approaches, guidelines, research, increasing the visibility of this on the pan-Canadian scene.

I know my officials have taken you through the list of things we have done and I think you would find it tiresome if I went through the details. We have not been inactive over the last five years. We have done a lot of things in terms of financing projects, funding conferences, publishing guides, bringing people together, and trying to focus attention. That is an important role for the Government of Canada.

I guess my frustration comes because I would like to see governments make more progress more quickly on a coherent approach to renewing medicare, developing objectives for strengthening services, and working together to achieve those objectives. We are involved in that very process with the provinces.

Why has this not happened before now? There are all kinds of reasons — political, fiscal, and practical. However, we are involved in it now; we have engaged. The first session in Markham was a little difficult, but we are underway and there are talks going on. We hope to get back to the table. I will bring to that table my concern that, working with the provinces, the appropriate attention is paid to a number of issues, including palliative care.

**Senator Corbin:** Just one comment. I thank you for that, Mr. Minister. I know that you are not in an ideal situation to deliver all of the goods. We are being televised. Canadian families, dying Canadians, and Canadians in pain could not care less about politics and shared jurisdictions.

Unfortunately, we cannot, as a committee, talk directly to the provinces. However, Canadians want good end-of-life palliative care. They could not care less about where the service comes from. However, they think that, in a country such as Canada, there is no reason why caring governments cannot get their heads together and come up with programs, training, facilities, hospital care, and community and home care, because they all want it.

Canadians want to be assured that after working 35, 40, or 50 years, giving their best to this country, that it will come to their assistance in their dying hours and make the passage easier. That is what this committee wants to tell you, the provincial ministers, the medical profession, and everyone.

Tous les jours, nous sommes confrontés à cette réalité. Ce n'est pas pour contourner votre question que je vous le dis, mais plutôt parce que j'essaie d'y répondre. La réalité est, en partie, que ce sont les provinces qui organisent et qui offrent les soins. C'est ainsi que le veut la Constitution et ainsi que le pays fonctionne.

Le gouvernement du Canada a-t-il un rôle à jouer là-dedans? Absolument. Quelle est la nature de ce rôle? Exactement ce que vous avez recommandé — des démarches coordonnées à l'échelle nationale, des lignes directrices, des activités de recherche, une augmentation de la visibilité de toute la problématique sur l'ensemble de la scène canadienne.

Je sais que mes collaborateurs vous ont exposé la liste de tout ce que nous avons fait et je vous épargnerai tous les détails. Nous n'avons pas été inactifs depuis cinq ans. Nous avons fait beaucoup sur le plan du financement de projets et de conférences, de la publication de guides, du rapprochement des gens, et d'efforts pour centrer leur attention sur ce thème. C'est un rôle important du gouvernement du Canada.

Je suppose que la frustration que je ressens vient du fait que j'aimerais voir les gouvernements faire plus de progrès, et plus rapidement, dans le sens d'une démarche cohérente en vue du renouvellement du système de santé, de la formulation d'objectifs de renforcement des services et de la collaboration à l'atteinte de ces objectifs. C'est exactement ce à quoi nous travaillons actuellement avec les provinces.

Pourquoi cela n'a-t-il pas été fait plus tôt? Pour toutes sortes de raisons — des raisons politiques, fiscales et pratiques. Par contre, le processus est engagé; nous nous y sommes attelés. La première séance, à Markham, a été un peu difficile, mais nous avons entamé le dialogue, qui se poursuit. Nous espérons revenir à la table de discussion. Je compte y exprimer mon intérêt pour qu'une attention suffisante soit portée à diverses questions, dont les soins palliatifs, dans le cadre des travaux avec les provinces.

**Le sénateur Corbin:** Je n'ai qu'une observation à faire. Je vous remercie, monsieur le ministre. Je sais que vous n'êtes pas dans la situation idéale pour tout dire. La séance est télévisée. Des familles du Canada, des Canadiens mourants et des Canadiens souffrants n'ont vraiment que faire de la politique et de la mise en commun des pouvoirs.

Malheureusement, nous ne pouvons pas, en tant que comité, nous adresser directement aux provinces. Et pourtant les Canadiens voudraient recevoir des bons soins palliatifs en fin de vie. Ils se moquent bien d'où viennent ces services. Cependant, ils trouvent que, dans un pays comme le Canada, il n'y a pas de raison pour que des gouvernements soucieux de leurs citoyens ne puissent pas cogiter ensemble à la création de programmes, de mesures de formation, d'installations, de programmes de soins hospitaliers, communautaires et à domicile, puisque c'est ce que veulent tous les Canadiens.

Les Canadiens voudraient être assurés qu'après avoir travaillé 35, 40 ou 50 ans, après avoir donné tout ce qu'ils ont à donner à leur pays, il viendra à leur aide à leurs dernières heures et leur facilitera le dernier soupir. C'est le message que veulent vous transmettre ce comité, les ministres des provinces, les membres de la profession médicale et tout le monde.

I think you are also part of the solution, as well as your provincial counterparts, the deans of medicine, community colleges, and everyone else. However, there must be a clear will and a concrete effort to put this thing together.

This committee has identified palliative care, leaving aside the financial questions, as the one area where Canadians would like to see some action.

**Mr. Rock:** It is one of many, and I could not agree with you more. We cannot allow jurisdictional issues or squabbles between governments to stand in the way of providing the care to which Canadians are entitled. That is particularly dramatic in end-of-life and palliative care contexts.

I can tell you, senator, that I am absolutely determined to see that we come out of this process with the provinces with concrete approaches to making those services available in a way that responds to the needs of Canadians. I believe that the provinces want to get there too, and I think that it can be achieved through working together. That is certainly what I am determined to do.

**Senator Roche:** Thank you. Minister, I flew from Edmonton to Ottawa this morning and picked up the *Edmonton Journal* on the plane, in which I read a headline that states: "Rock faces heat over palliative care, euthanasia policies."

I do not know about you, but I find the temperature in the room fairly agreeable at this moment.

**Mr. Rock:** Perhaps the people with their coats still on are feeling the heat back there. I do not know.

**Senator Roche:** The other part of the headline stated: "Senate committee set to attack inaction when he gives progress report."

I do not know whether this committee will attack you or not. What I do know is that the overwhelming amount of evidence received by the subcommittee and that brought us to this point, made the observation, from several different perspectives, that the government did not respond to the 1995 report in anything approaching a satisfactory manner.

In addressing that this afternoon, I understood you to say that while the government has done certain things, you agree that much more needs to be done — put it that way.

**Mr. Rock:** Absolutely.

**Senator Roche:** I understood you to say that the 1995 report was sidelined for a combination of political, fiscal, and practical reasons. Did you mean to give equal weight to the words "political, fiscal, and practical," and would you explain what you really mean by "political"? Is this the jurisdictional or the provincial issue, or something else? How serious is the fiscal issue with respect to palliative care's share of the overall health budget? What does "practical" mean?

Je pense que vous êtes aussi partie de la solution, avec vos homologues provinciaux, les doyens du milieu médical, les représentants des collèges communautaire et tout le monde. Cependant, il faut une volonté claire et un effort concret pour que tout cela puisse se réaliser.

Notre comité a déterminé que les soins palliatifs, mis à part l'aspect financier, sont l'un des domaines où les Canadiens tiennent à voir la situation évoluer.

**M. Rock:** C'en est un parmi tant d'autres, et je ne peux qu'être parfaitement d'accord avec vous. Nous ne pouvons pas permettre aux questions de juridiction ni aux chicanes entre les gouvernements de faire obstacle à la prestation des soins auxquels les Canadiens ont droit. C'est particulièrement dramatique dans le contexte de la fin de la vie et des soins palliatifs.

Je peux vous dire, sénateur, que je suis tout à fait résolu à veiller à ce qu'à la fin de ce processus avec les provinces, nous ayons cerné des moyens concrets de rendre ces services accessibles d'une manière qui réponde aux besoins des Canadiens. Je pense que les provinces y sont aussi déterminées, et je crois que nous pouvons y parvenir en collaborant. Moi en tout cas, j'y suis bien résolu.

**Le sénateur Roche:** Merci, monsieur le ministre. Dans l'avion qui m'amenait à Ottawa d'Edmonton, ce matin, j'ai pris l'*Edmonton Journal*, qui annonçait en manchettes: «Le ministre Rock au cœur d'un chaud débat sur les politiques relatives aux soins palliatifs et à l'euthanasie».

Je ne sais pas ce que vous en pensez, mais il me semble que la température est encore assez agréable dans cette pièce.

**M. Rock:** Peut-être que ceux qui ont encore leurs manteaux sur le dos éprouvent cette chaleur. Je ne sais pas.

**Le sénateur Roche:** L'autre partie de ces manchettes disait: «Le comité du Sénat prêt à s'en prendre à son inaction lorsqu'il déposera son rapport d'étape».

Je ne sais pas si le comité compte vous attaquer ou pas. Ce que je sais, par contre, c'est que dans la multitude de documents qu'a reçus le sous-comité jusqu'ici on trouvait la remarque, exprimée de divers points de vue, que les actions du gouvernement à la suite du rapport déposé en 1995 ont été très loin d'être satisfaisantes.

À ce propos, je vous ai entendu dire tout à l'heure que bien que le gouvernement ait fait certaines choses, vous convenez qu'il reste encore beaucoup à faire — si on peut dire.

**M. Rock:** C'est bien cela.

**Le sénateur Roche:** J'ai cru comprendre que vous disiez que le rapport de 1995 a pris une voie secondaire pour diverses raisons d'ordre politique, fiscal et pratique. Vouliez-vous dire par là que les raisons politiques, fiscales et pratiques revêtaient toutes la même importance, et pouvez-vous expliquer ce que vous entendez par «politique»? Est-ce que c'est le problème de juridiction, avec les provinces qui résistent, ou s'agit-il d'autre chose? Quelle est la part du problème d'ordre fiscal dans la portion du budget attribuée aux soins palliatifs? Quel sens donnez-vous au terme «pratique»?



**Mr. Rock:** The amount for palliative care in the overall health budget is for the provinces to decide, of course. I was referring to the fact that over the last almost three years since I became Minister of Health, we have been focused on putting more money into the health transfers to the provinces.

Indeed, we have increased the transfer very significantly since 1997. We have increased the health transfers to the provinces in each of the budgets since that year. In the February 1999 budget, there was a commitment of \$11.5 billion over five years, which was just for health. In this past budget, \$2.5 billion was made available for health and education.

We are even now in discussions with the provinces on increased transfers for health. As the Prime Minister has said, we want to sign on to a long-term commitment for increased transfers for health in coordination with a plan for strengthening the system into the future.

I guess my reference was to the fact that much of our attention has been focused on putting more money into the health transfer. That has been a preoccupation. Of course, how much of that money is for palliative care is for the provincial governments and ministers to determine.

We have also been busy in other areas, and I mentioned health research. We took your recommendations on research and have actually made very significant improvements in the research enterprise federally with the creation of institutes and increased funding throughout the country. I think that that has been very good.

In our own jurisdiction, which is aboriginal health, First Nations health in First Nations territory, we have devoted significantly more money to home and community care. Funding in that context will rise to about \$90 million a year starting in 2002, including end-of-life care.

However, the difficulties that I have raised have been in each of those areas. There has been work done on the fiscal side. Politically, it has been an issue between Ottawa and the provinces on who does what, and what is Ottawa's role in saying that more attention should be paid to palliative care by the provinces.

Issues involving Ottawa's role have arisen. You are right to say that I noted from the beginning that there is still much work to do on the recommendations that you made. We do not consider the job completed and we are determined to address your recommendations on a continuing basis.

**Senator Roche:** I do not ordinarily quote newspaper stories as the basis for my questions in committees. However, I will make an exception in the next question because I think the lead story across Canada today, which has shown up in several newspapers, points exactly to the dilemma that we are facing. The writer in the *Edmonton Journal* states:

**M. Rock:** La portion du budget global qui est attribuée aux soins palliatifs relève des provinces, bien entendu. Je faisais allusion au fait que depuis presque trois ans que je suis ministre de la Santé, nous nous efforçons d'augmenter les transferts aux provinces relatifs à la santé.

D'ailleurs, depuis 1997, les transferts aux provinces relatifs à la santé ont augmenté à chaque budget. Dans le budget présenté en février 1999, 11,5 milliards de dollars étaient prévus sur cinq ans rien que pour la santé. Dans le dernier budget, 2,5 milliards de dollars ont été réservés à la santé et à l'éducation.

Même encore maintenant, nous discutons avec les provinces d'augmentation des transferts relatifs à la santé. Comme l'a dit le premier ministre, nous voulons prendre un engagement à long terme visant l'augmentation des transferts relatifs à la santé, en coordination avec un plan de renforcement du système dans le futur.

Je suppose que l'allusion que je faisais se rapportait au fait que notre attention a beaucoup été monopolisée par l'augmentation des transferts relatifs à la santé. Ça a été au centre des préoccupations. Cependant, c'est sûr que de sont les gouvernements et les ministres provinciaux qui déterminent quelle proportion de ces transferts est attribuée aux soins palliatifs.

Nous avons aussi été occupés par d'autres aspects, comme la recherche sur la santé. Nous avons suivi vos recommandations sur la recherche et avons apporté d'importantes améliorations dans les activités de recherche à l'échelle fédérale, avec la création d'instituts et l'augmentation du financement dans tout le pays. Je crois que cela a été très positif.

Dans le secteur qui relève de notre propre autorité, la santé des autochtones, la santé des Premières nations sur les territoires des Premières nations, nous avons mis beaucoup plus d'argent sur les soins à domicile et dans la communauté. Le financement de ces activités augmentera d'environ 90 millions de dollars par année à compter de 2002, et cela comprend les soins à la fin de la vie.

Cependant, les difficultés dont j'ai parlé se posent dans chacun de ces domaines. Certaines choses ont pu être faites du côté fiscal. Sur le plan politique, le problème entre Ottawa et les provinces est de savoir qui fait quoi, et de quelle autorité le gouvernement fédéral peut-il dire aux provinces qu'elles devraient accorder plus d'attention au domaine des soins palliatifs.

Des problèmes ont été soulevés relativement au rôle d'Ottawa. Vous avez raison, je dis depuis le début qu'il reste encore beaucoup à faire en ce qui concerne vos recommandations. Nous n'estimons pas notre travail terminé et nous sommes résolus à suivre vos recommandations de façon continue.

**Le sénateur Roche:** Je n'ai pas l'habitude de fonder mes questions sur les manchettes des journaux dans les débats des comités. Cependant, je ferai exception à cette règle pour la prochaine question parce que je crois que les principales manchettes au Canada aujourd'hui, qu'ont repris plusieurs journaux, traitent justement du dilemme qui nous occupe. Dans l'article de l'*Edmonton Journal*, on lit:



Thousands of Canadians are suffering needlessly as they die because governments are afraid of legislating rules for euthanasia and don't have the political will to make palliative care a priority...

All of us in this room recognize that the reporter has his apples and oranges mixed up in that one sentence. Indeed, the subcommittee has gone out of its way to emphasize to all the witnesses that we are concentrating on ways to enhance palliative care because we think that is a necessary thing to do for the sake of Canadian human dignity and so on. Yet the committee was divided in 1995 on questions related to euthanasia and assisted suicide.

I have placed the issue before the committee, and it is highlighted precisely by this reporter's language: namely, that governments are afraid to move on palliative care because they fear they will get into the realms of assisted suicide and euthanasia. That is a completely different situation, recognizing that there is a certain blurring between good palliative care on the one hand, which allows a person to die in dignity, and active steps to terminate life on the other, which falls into the categories of euthanasia and assisted suicide.

I should like to hear from the minister whether or not there is any truth to the rumour about governments holding back on putting needed resources into palliative care because they are afraid of getting into the subjects of assisted suicide and euthanasia.

**Mr. Rock:** I can only speak for the government of which I am a member. I do not speak for any other government in the country, nor do I attribute any attitude, concern, or belief to any other government in the country.

I have not discussed it with them and I have no idea if it is true. I can tell you that as far as the government of which I am a part is concerned, there is no hesitation about dealing with palliative care issues for fear that we might have to deal with euthanasia. They are two different things.

Palliative care, senator, is medical care for the dying. It has nothing to do with euthanasia or assisted suicide or any other such issue. Care for the dying is part of health care services and should be treated that way.

I am not sure I could devote more resources to palliative care even if I wanted to. We transfer dollars to the provincial health ministers, who do provide care and decide on their priorities. Thus, you might want to ask a provincial minister about the amount of money devoted to palliative care.

The Government of Canada believes that palliative care issues must be dealt with. We are not in any way reluctant to do so because of suggestions that someone might raise the subject of euthanasia. We are extremely involved in policy issues on palliative care and in pilot projects on how to better deliver it.

«Des milliers de Canadiens souffrent inutilement en mourant parce que les gouvernements craignent de légiférer sur l'euthanasie et n'ont pas la volonté politique de mettre les soins palliatifs au rang des priorités [...]»

Nous pouvons tous ici reconnaître que l'auteur de l'article, dans cette seule phrase, mêle les pommes avec les oranges. De fait, le sous-comité s'est donné beaucoup de peine pour faire comprendre à tous les témoins que nous nous concentrons sur des moyens d'améliorer les soins palliatifs parce que nous pensons que c'est nécessaire au nom de la dignité humaine, et cetera. Cependant, le comité était divisé en 1995 sur les questions liées à l'euthanasie et au suicide assisté.

J'ai porté la question devant le comité, et l'auteur de cet article le dit sans mâcher ses mots: les gouvernements ont peur de faire quoi que ce soit au sujet des soins palliatifs parce qu'ils craignent d'empiéter sur le terrain du suicide assisté et de l'euthanasie. C'est tout autre chose, bien qu'on puisse reconnaître que la frontière est un peu floue entre les bons soins palliatifs d'un côté, qui permettent à quelqu'un de mourir avec dignité et, de l'autre, des mesures actives visant à mettre fin à la vie, qui tombent dans la catégorie de l'euthanasie et du suicide assisté.

J'aimerais entendre du ministre s'il y a quelque vérité dans la rumeur selon laquelle les gouvernements hésitent à octroyer les ressources nécessaires aux soins palliatifs parce qu'ils craignent de s'engager sur le terrain du suicide assisté et de l'euthanasie.

**M. Rock:** Je ne peux que parler au nom du gouvernement que je représente. Je ne peux rien dire pour les autres gouvernements du pays, ni leur attribuer aucune intention, aucune préoccupation ni aucune conviction.

Je n'en ai pas discuté avec eux et je ne sais absolument pas si c'est vrai. Je peux vous dire qu'en ce qui concerne le gouvernement dont je fais partie, il n'hésite aucunement à aborder la question des soins palliatifs par crainte que de devoir traiter aussi de l'euthanasie. Ce sont deux choses bien distinctes.

Les soins palliatifs, monsieur le sénateur, ce sont des soins médicaux aux mourants. Cela n'a rien à voir avec l'euthanasie ni avec le suicide assisté, ou avec quoi que ce soit du genre. Les soins aux mourants font partie intégrante des services des soins de santé et devraient être traités comme tels.

Je ne suis pas sûr que je pourrais consacrer plus de ressources aux soins palliatifs même si je le voulais. Nous transférons de l'argent aux ministres provinciaux de la Santé, qui le répartissent et déterminent leurs priorités. C'est pourquoi vous devriez peut-être poser à un ministre provincial cette question sur la portion des transferts qui est consacrée aux soins palliatifs.

Le gouvernement du Canada est convaincu de la nécessité de régler les questions relatives aux soins palliatifs. Nous n'hésitons absolument pas à le faire parce que quelqu'un prétend que cela pourrait être lié au sujet de l'euthanasie. Nous participons très activement au débat sur les politiques relatives aux soins palliatifs et aux projets pilotes en vue de déterminer quel est le meilleur mode possible de prestation de ces soins.

We do not deliver services, but we can fund pilot projects to help us learn from demonstrations what methods of delivery are the best and most effective. That is what the Health Transition Fund was all about. However, we have not been in the least reluctant to deal with the issue for the reasons suggested in your question.

**Senator Roche:** I welcome your answer. My final question is, do you or your associates here, or by extension in the department, have any research that would bring forward some informed views or evidence that the enhancement of palliative care reduces requests for assisted suicide and euthanasia? Did I put that clearly enough?

**Mr. Rock:** I think I understood your question. However, I am not aware of any such literature. Perhaps my colleagues might know if there is any research on that point. I invite them to respond if they do.

**Mr. Cliff Halliwell, Director General, Applied Research and Analysis Directorate, Information, Analysis and Connectivity Branch, Health Canada:** I am not aware of any.

**Ms Barbara Ouellet, Director of Home Care and Pharmaceuticals, Health Care Directorate, Policy and Consultation Branch, Health Canada:** I am not sure that there is research on that specific question. However, we do know that the converse appears to be at least a fear. Without available treatments, people may indeed fear dying at home and on their own. For that reason, one of the projects that we funded under our Population Health Fund looked at the use of sedation and some of the challenges and complexities in determining the fine line between providing adequate support during dying but not inadvertently hastening death.

**Senator Roche:** You said that you are inclined to view the converse as being true. How do you know that the demand for assisted suicide is increased by a lack of good palliative care?

**Ms Ouellet:** As I said, we do not have specific research on that topic. This is really anecdotal evidence that people are concerned about the consequences of dying without adequate palliative care.

**Senator Roche:** Finally, to the minister, is it possible that Canadian understanding of the need to resource palliative care and get all governments to give it a higher priority would be helped by adducing more evidence to support the belief that good palliative care reduces the demand for assisted suicide and euthanasia?

**Mr. Rock:** I think it is worth considering, senator. However, I do not think that we need to look for reasons to make good palliative care available. We have plenty of those, and that should be our focus. It is worthwhile in and of itself.

Nous n'offrons pas de services, mais nous pouvons financer des projets pilotes qui peuvent contribuer à cerner quelles méthodes de prestation sont les meilleures et les plus efficaces. C'était exactement l'objet du Fonds pour l'adaptation des services de santé. Cependant, je peux vous affirmer que nous n'avons absolument pas été réticents à traiter de la question pour les raisons que vous laissez supposer.

**Le sénateur Roche:** Je suis heureux d'entendre votre réponse. Ma dernière question est la suivante: est-ce que vous, vos collaborateurs ici ou, par extension, ceux de votre ministère, avez des documents de recherche où sont exposés des points de vue éclairés ou des éléments pouvant démontrer que l'amélioration des soins palliatifs réduirait la demande d'aide au suicide et d'euthanasie? Est-ce que ma question est assez claire?

**M. Rock:** Je crois l'avoir comprise. Cependant, je ne suis pas au courant de l'existence de tels documents. Peut-être mes collègues savent-ils si ce genre de recherches ont été faites. Je les invite à y répondre s'ils le savent.

**M. Cliff Halliwell, directeur général, Direction de la recherche appliquée et de l'analyse, Direction générale de l'information, de l'analyse et de la connectivité, Santé Canada:** Je n'en connais pas.

**Mme Barbara Ouellet, directrice, Division des soins à domicile et des produits pharmaceutiques, Direction des soins de santé, Direction générales des politiques et de la consultation, Santé Canada:** Je ne suis pas sûre qu'il y ait eu de recherches sur ce sujet précis. Cependant, nous savons que l'inverse semble susciter au moins quelques craintes. Sans accessibilité aux traitements, les gens peuvent en fait craindre de mourir sans assistance chez eux. Pour cette raison, l'un des projets que nous avons financés avec notre Fonds pour la santé de la population visait l'examen de l'utilisation des sédatifs et de certains des problèmes et des défis que pose la définition de la démarcation très mince entre la prestation d'un soutien adéquat aux mourants et le fait d'en hâter le décès par inadvertance.

**Le sénateur Roche:** Vous avez dit trouver quelque vérité à la théorie inverse. Comment pouvez-vous savoir que le manque de soins palliatifs fait augmenter la demande d'assistance au suicide?

**Mme Ouellet:** Comme je vous l'ai dit, nous n'avons pas effectué de recherches spécifiques sur ce sujet. Seules des données non scientifiques nous donnent à penser que les gens s'inquiètent des conséquences du fait d'être mourant sans recevoir de soins palliatifs adéquats.

**Le sénateur Roche:** En dernier lieu, je m'adresse au ministre, serions-nous mieux en mesure de faire comprendre aux Canadiens le besoin de financer les soins palliatifs et d'amener les gouvernements à mettre la question au rang des hautes priorités si nous présentions plus d'éléments probants pour soutenir la théorie que de bons soins palliatifs réduisent la demande d'aide au suicide et d'euthanasie?

**M. Rock:** Je pense que cela vaudrait la peine d'y réfléchir, sénateur. Cependant, je ne crois pas que nous ayons besoin de chercher de bonnes raisons pour fournir de bons soins palliatifs. Nous en avons déjà suffisamment, et nous devrions nous concentrer là-dessus. Rien que celles-là en valent la peine.



**The Chairman:** Before I turn to a second round, I wish to ask some questions.

Mr. Minister, there have been significant changes in the way health care expenditures have been made since the original Canada Health Act, if you want to go back to the 1960s.

The federal government decided to fund hospitals and physician services because that sector was consuming the greatest amounts of money and nothing else was even close. We now know that drugs are draining more out of the health care budget than physicians.

Yet in your discussions with the provinces, you made frequent reference to the need for funding for and a coordinated effort towards home care. I did not hear anything about the national forum's recommendation that we institute a national pharmacare program. Is there a particular reason why that is not part of the debate with the provinces or do you place greater priority on home care than on pharmacare?

**Mr. Rock:** In fact, Senator Carstairs, the provinces raise these pharmaceutical issues every time we meet. They figured very prominently in the discussions in Markham. Many of the provinces told me that their pharmaceutical costs are now rising at the rate of 16 per cent a year. It is a major cost driver. Right now the provinces are in the process of preparing a report for their premiers on cost drivers in the health care system, and I expect that pharmaceutical costs will be one of the main focuses of that report. Therefore, it is very much a concern.

The provinces also raise it in the context that Health Canada approves new drugs based on safety and efficacy. That is our legal mandate, but it is then up to the provinces to decide whether to add those drugs to their formularies — in other words, whether or not to pay for them. The provinces find themselves under significant pressure to pay for those new drugs, some of which are extremely expensive, even though there might be a very marginal difference in their effectiveness compared to other drugs already on the market. They find this extremely difficult.

If one province accedes to the demand that a drug be added, all the others feel they must do the same, and hence costs keep going up. They want to talk about this and how to approach these pharmaceutical issues from the point of view of making sure that our system is sustainable in the long term. Indeed, a federal-provincial committee has been working on these pharmaceutical issues for some time, trying to find solutions to the dilemma of getting Canadians the most recent, effective, and current pharmaceutical treatments, but at the same time, in a way that will allow us to keep our public health care system.

I do not want you to think that pharmaceutical issues do not arise, because they certainly do. They are raised by the provinces because of this real concern. In fairness, I should also point out

**La présidente:** Avant de faire un deuxième tour, j'aimerais poser quelques questions.

Monsieur le ministre, d'énormes changements sont survenus dans le mode de dépenses sur les soins de santé depuis qu'existe la Loi canadienne sur la santé, si on remonte jusqu'aux années 60.

Le gouvernement fédéral a décidé de financer les hôpitaux et les services des médecins parce que les dépenses dans ce secteur étaient incomparables à aucun autre. Nous savons maintenant que les médicaments consomment une plus grande part du budget du système de santé que les médecins.

Pourtant, en parlant des provinces, vous faites souvent allusion au besoin de financement des soins à domicile et d'un effort coordonné sur ce plan. Je n'ai rien entendu au sujet de la recommandation du comité national visant la mise sur pied d'un régime national d'assurance-médicaments. Y a-t-il une raison particulière pour laquelle il n'en est pas question dans les discussions avec les provinces, ou accordez-vous une plus grande priorité aux soins à domicile qu'à l'assurance-médicaments?

**M. Rock:** En fait, sénateur, les provinces parlent de ces questions de régime d'assurance-médicaments à chacune de nos rencontres. Elles ont dominé les débats à Markham. Plusieurs provinces m'ont signalé que leurs coûts en médicaments augmentent au rythme de 16 p. 100 par année. C'est un facteur de coût important. En ce moment même, les provinces sont en train de préparer un rapport à l'intention de leurs premiers ministres sur les facteurs générateurs de coûts dans le système de santé, et je m'attends à ce que les coûts des médicaments soient l'un des principaux sujets de ce rapport. Par conséquent, c'est bien un facteur de préoccupation.

Les provinces ont aussi soulevé la question relativement au fait que Santé Canada approuve de nouveaux médicaments en se fondant sur des facteurs de sécurité et d'efficacité. C'est le mandat qui nous a été attribué légalement, mais il incombe cependant aux provinces de décider si elles veulent ajouter ces médicaments à leurs formularies — autrement dit, si elles veulent ou non les rembourser. Les provinces subissent de fortes pressions en faveur du remboursement de ces nouveaux médicaments, dont certains sont extrêmement coûteux, même s'il n'y a parfois qu'une différence très marginale dans leur degré d'efficacité comparativement à d'autres médicaments qui sont déjà sur le marché. Elles trouvent tout cela très difficile.

Si une province accède à la demande d'ajout d'un médicament, toutes les autres se sentent obligées de faire de même, et les coûts continuent de monter. Les provinces veulent en discuter, à la lumière aussi du fait qu'elles voudraient assurer la viabilité de notre système à long terme. En fait, un comité fédéral-provincial se penche déjà depuis quelque temps sur ces questions de médicaments, et il essaie de trouver des solutions au dilemme qu'il y a à vouloir fournir aux Canadiens les traitements les plus récents, les plus efficaces et les plus pointus possible tout en préservant notre régime public de santé.

Je ne voudrais pas que vous pensiez que les questions de médicament sont négligées, parce que ce serait faux. Les provinces en parlent, parce que c'est une préoccupation réelle.



that sometimes a drug can either postpone or render unnecessary other forms of treatment, whether that be surgery or something else. Think about the breakthroughs in ulcer treatment, for example. It may be that the use of pharmaceuticals in the treatment of ulcers has coincided with a better understanding of how ulcers are caused and how they are best treated. Other forms of treatment, such as surgery, have perhaps diminished. Thus, I think we must bear in mind the overall picture. There are issues of utilization, prescription practices, and a better understanding, on the part of the public, of how pharmaceuticals are used. All of these factors play into a complex picture, but in responding to your question, I wanted to make clear that it is very much a part of our discussions. Was it the year before last that we had a national conference on pharmacare? The time has gone by so quickly.

**Ms Ouellet:** 1998.

**Mr. Rock:** We had a national conference on pharmacare to look at how to ensure that price is not a barrier when Canadians want access to the pharmaceuticals that they need. One of the findings at that conference was that 88 per cent of the population is covered in one way or another for pharmaceutical costs — either by reason of their financial circumstance, their age, or public or private plans. That disguises the fact that many of those people are also paying deductibles or copayments, or there are rules within the insurance scheme that require them to pay something. These issues are very much alive in the discussions between provincial and federal governments and that we regularly have with the public and non-government organizations. We are talking about managing pharmaceutical costs. I do not want you to think that it is not on the agenda, because it very much is.

**The Chairman:** Witnesses have raised with us the inextricable link between the costs of drugs and the provision of home care. For example, palliative care patients who decide that they want to die at home not only need all of the support such as, perhaps, a hospital bed, a lifting machine, wheelchairs, et cetera, but they also need drugs. If they do not have coverage for drugs, then they are forced to return to a hospital setting, because if you are in hospital in this country, your drugs are covered, but if you are not, they may not be.

Interestingly enough, you have given me a much higher percentage than we have heard before with respect to the number of Canadians that are covered in any way, shape or form. That is something we will have to work out in the other study. The reality is that we were told that patients returned to the hospital not because they wanted to, but because they did not have coverage for their drugs.

Pour être juste, je devrais aussi souligner que, parfois, un médicament peut soit retarder le recours à une autre forme de traitement, comme la chirurgie ou autre chose, soit même le rendre inutile. Il n'y a qu'à penser aux progrès décisifs qui ont été réalisés dans le traitement des ulcères, par exemple. Il est bien possible que le recours aux médicaments dans le traitement des ulcères a coïncidé avec une meilleure compréhension de leur cause et des meilleures méthodes de traitement. D'autres formes de traitement, comme la chirurgie, ont peut-être diminué. C'est pourquoi je crois qu'il faut garder à l'esprit la situation d'ensemble. Toutes sortes de facteurs entrent en compte, dont l'utilisation, les pratiques de rédaction d'ordonnance et une meilleure compréhension, de la part du public, du mode d'administration des médicaments. Tous ces facteurs font partie d'une situation complexe, mais pour répondre à votre question, je tiens à ce qu'il soit bien clair que nous en parlons dans nos discussions. C'est bien il y a deux ans qu'il y a eu une conférence nationale sur le régime d'assurance-médicaments? Le temps passe si vite.

**Mme Ouellet:** C'était en 1998.

**M. Rock:** Nous avons tenu une conférence nationale sur le régime d'assurance-médicaments dans le but de voir comment nous pourrions faire en sorte que les prix ne soient pas un obstacle lorsque les Canadiens veulent accéder aux médicaments dont ils ont besoin. L'une des choses que nous avons découvertes, lors de cette conférence, est que 88 p. 100 de la population peut, par un moyen ou un autre, se faire rembourser les médicaments — soit à cause de leur situation financière, de leur âge, ou du fait qu'ils sont protégés par un régime public ou privé d'assurance. Cela n'empêche pas qu'ils doivent aussi payer des franchises ou des quotes-parts, ou que leur régime d'assurance comporte des règles qui les obligent à déboursier certains montants. Ces questions font l'objet de débats animés entre les gouvernements provinciaux et fédéral, et d'autres que nous tenons régulièrement avec des organismes publics et non gouvernementaux. Nous parlons de gestion des coûts des médicaments. Je ne voudrais pas que vous pensiez que ce n'est pas à notre programme, parce que ce serait faux.

**La présidente:** Les témoins nous ont fait remarquer le rapport indéniable entre les coûts des médicaments et la prestation de soins à domicile. Par exemple, les patients qui reçoivent des soins palliatifs et qui décident de mourir à la maison n'ont pas seulement besoin de tout un équipement comme, par exemple, un lit d'hôpital, un dispositif de levage, un fauteuil roulant, et cetera, mais aussi de médicaments. S'ils n'ont pas d'assurance-médicaments, ils sont obligés de retourner en milieu hospitalier, parce qu'au Canada, si vous êtes à l'hôpital, vos médicaments vous sont fournis gratuitement, mais si vous n'y êtes pas, ce n'est pas toujours le cas.

Fait curieux, vous avez cité un pourcentage bien plus élevé que ce que j'avais entendu auparavant sur le nombre de Canadiens qui disposent d'un régime de remboursement quelconque. Nous devons examiner cette question dans le cadre de l'autre étude. La vérité, c'est qu'on nous a dit que les patients retournent à l'hôpital non pas parce qu'ils le veulent, mais parce que leurs médicaments ne leur sont pas payés.

**Mr. Rock:** One of the reasons I am interested in home and community care is that I think that it is very unfair to have a system of public health insurance that covers hospital costs, and then watch new technology and medical practices shorten hospital stays. Across the country, an average of 75 per cent of surgery is done on an out-patient basis — in, in the morning, and out, in the afternoon. Then, as we see services move outside the hospital, coverage does not follow and people are left without the benefit of public insurance for things that used to be covered in the hospital. Drugs is a very good example. I have read the suggestion by some commentators that home and community care should be designed so that at least it picks up the cost of drugs that you used to receive in the hospital. I think that governments will have to look at that kind of issue eventually.

A kind of incidental de-insuring of services has gone on as service has moved outside of the places where the Canada Health Act provides for coverage. One of the reasons that we have seen private spending go up in Canada over the last decade at a faster rate than other OECD countries — it is now over 30 per cent — is that the focus of service has moved outside the hospital to other locations and coverage has not followed. It is a reality with which governments have to deal.

**Senator Beaudoin:** I agree with your approach that palliative care is such a valuable objective in itself that there is no need to ask questions about whether it is related to some other aspect — for example, euthanasia and assisted suicide. I think our decision to talk only about the points on which we were unanimous was a very good one. That offers the best chance of success. If we all agree on something, we will find a solution. It is part of politics, of course, that we do not use the same way, the same means, et cetera. The provinces have their own objectives, and the federal authority may have the same objective, but perhaps the means are different.

The chances for success are greater on the points on which we will make some suggestions and recommendations. We all agreed on those points in 1995, and we still agree on them in 2000.

I do not think it is only a question of money. I think it is a little more than that. Money is always involved, of course, but there are the means we use to reach a goal. My guess is that the provinces are not unanimous on those means and objectives. However, you seem to be optimistic that we will succeed and I think we will too. The need is there and the population is strongly in favour. If we all agree on the objectives, then we should certainly find a solution somewhere. I would like to hear your comments on this. My impression is that it is a question of organization.

**Mr. Rock:** I think that is right, senator. The Canadian public will insist that governments get their act together and come up with a coherent approach to combining money with ingenuity to produce a better health care system. That is what we are determined to do. It is not just a question of spending more money and making our health care system more expensive.

**M. Rock:** L'une des raisons pour lesquelles je m'intéresse aux soins à domicile et dans la communauté est que je pense qu'il est très injuste que nous ayons un régime d'assurance publique qui couvre les coûts des hôpitaux tandis que la nouvelle technologie et les nouvelles pratiques médicales permettent de réduire les séjours à l'hôpital. Dans tout le pays, 75 p. 100 en moyenne des opérations chirurgicales se font sans hospitalisation — on entre le matin et on sort l'après-midi. Cependant, alors que les services sortent de l'hôpital, la protection ne suit pas et les gens se retrouvent sans l'avantage d'une assurance publique pour des choses qui, auparavant, étaient offertes gratuitement à l'hôpital. Les médicaments en sont un excellent exemple. J'ai lu la suggestion de certains commentateurs selon laquelle les soins à domicile et dans la communauté devraient être conçus de manière, au moins, à couvrir les coûts des médicaments qu'on nous administrait auparavant à l'hôpital. Je crois que les gouvernements devront se pencher sur ce genre d'enjeu à un moment donné.

On a assisté à une sorte de désassurance de services qui étaient jadis assurés en vertu de la Loi canadienne sur la santé. Si les dépenses privées ont augmenté plus vite au Canada, au cours des dix dernières années, que dans d'autres pays de l'OCDE — elles s'élèvent maintenant à plus de 30 p. 100 —, c'est parce que les services sont fournis non plus par les hôpitaux, mais par d'autres établissements, de sorte qu'ils ne sont plus assurés. C'est une réalité avec laquelle les gouvernements doivent composer.

**Le sénateur Beaudoin:** La prestation de soins palliatifs est un objectif tellement important en soi qu'il est inutile de se demander s'il est lié à d'autres aspects — par exemple, l'euthanasie et l'aide au suicide. Je pense que nous avons eu raison de discuter uniquement des points sur lesquels il y avait consensus. Nous aurons ainsi plus de chances de trouver des solutions. Si nous arrivons à nous entendre, nous finirons par en trouver. Le fait que nous n'utilisons pas les mêmes démarches, les mêmes méthodes, et cetera, fait partie de la politique. Les provinces ont leurs propres objectifs, et le gouvernement fédéral a peut-être les mêmes, sauf qu'il utilise peut-être des moyens différents pour les atteindre.

Nous aurons plus de chances de trouver des solutions, de formuler des suggestions et des recommandations sur ces points. Nous l'avons fait en 1995, et nous le referons cette année.

Ce n'est pas seulement une question d'argent. C'est plus que cela. L'argent est un facteur, bien sûr, mais il y a aussi les moyens que nous utilisons pour atteindre un objectif. Or, les provinces ne s'entendent pas sur ces moyens et ces objectifs. Toutefois, vous semblez croire que nous allons y arriver, et moi aussi. Le besoin existe, et nous avons l'appui de la population. Si nous arrivons à nous entendre sur les objectifs, nous finirons par trouver une solution. J'aimerais avoir votre opinion là-dessus. J'ai l'impression que c'est surtout une question d'organisation.

**M. Rock:** Vous avez raison, sénateur. La population canadienne insistera pour que les gouvernements adoptent une approche cohérente quant à l'utilisation des fonds et fassent preuve d'ingéniosité dans le but d'améliorer le système de santé. C'est ce que nous comptons faire. Il ne s'agit pas tout simplement de dépenser plus et de rendre notre système encore plus coûteux.



**Senator Beaudoin:** To a certain extent, it may be.

**Mr. Rock:** Yes. I am an advocate for money for health care in the transfers to the provinces. However, at the same time, the Prime Minister has said that we want that additional money to go toward a coherent plan for producing better outcomes, which is what this is all about. It is not just a question of spending for its own sake. It is spending to produce better health outcomes for Canadians. There are broad areas of agreement between the federal and provincial governments on what those changes ought to be.

The health care system is even now being reformed by provinces. Innovation in the provinces is leading the way. The Government of Canada wants to get behind those changes, to broaden and accelerate the innovations provinces have already adopted, so that we can hasten the improvement of the health care system.

**Senator Beaudoin:** At noon today I was listening to Radio Canada. They spoke about the report released today in Quebec on palliative care. I was a little surprised — even scandalized — by the fact that we are not devoting very much money to the question of pain and suffering. That is something we can do. We are a very rich country, of which the provinces are part. We have that money.

Who is against palliative care? Everyone is for palliative care. How is it that we have spent so little on a subject which is of concern, to a certain extent at least, to everyone in this country?

**Mr. Rock:** That is a good question. Have provincial ministers appeared before your committee?

**The Chairman:** Not this time. The special Senate committee did hear them.

**Mr. Rock:** Did you raise with them provincial spending on palliative care? The same might be said of orthopaedics or obstetrics. How much money do the provincial governments devote to the treatment of diabetics? I think I would be reluctant to talk about the allocation of provincial dollars to priorities. However, I think provincial ministers might be prepared to do so.

Am I right in saying that during your first set of hearings in 1995 you actually had provincial ministers before you?

**The Chairman:** Yes. We wrote to all of them this time and solicited some information from them on the progress they have been making. We have, of course, heard from nurses and doctors with respect to what is going on in their particular provinces. Unfortunately, what we learned is that, with the health care cuts that were going on generally across the country, palliative care was almost hit harder because it was such a new field. There were few palliative care beds to begin with. When those few beds experienced cuts, the system broke down in some cases. There just simply were no resources available for palliative care.

We have also learned that palliative care is still not a legally recognized medical specialty in Canada. There are doctors who provide palliative care, but it is not recognized like obstetrics and

**Le sénateur Beaudoin:** Dans une certaine mesure, oui.

**M. Rock:** Je suis d'accord pour dire qu'il faut augmenter les transferts relatifs au financement de la santé. Toutefois, le premier ministre a dit que ces ressources additionnelles doivent servir à établir un plan cohérent en vue d'obtenir de meilleurs résultats. C'est de cela dont il est question ici. Il ne s'agit pas tout simplement de dépenser pour dépenser. Il faut dépenser pour offrir de meilleurs soins de santé aux Canadiens. Le gouvernement fédéral et les provinces s'entendent de manière générale sur les changements qui devraient être apportés.

Les provinces ont entrepris de réformer le système de santé. Elles mettent l'accent sur l'innovation. Le gouvernement du Canada veut appuyer et accélérer les réformes entreprises par les provinces pour améliorer le système de soins de santé.

**Le sénateur Beaudoin:** J'écoutais Radio-Canada ce midi. Ils parlaient du rapport sur les soins palliatifs qui avait été rendu public, aujourd'hui, au Québec. J'ai été un peu étonné — voire scandalisé — d'apprendre qu'on y consacrait si peu d'argent. Nous pouvons faire quelque chose à ce chapitre. Nous sommes un pays très riche. Les ressources ne manquent pas.

Qui s'oppose aux soins palliatifs? Tout le monde est en faveur de la prestation de tels soins. Comment se fait-il qu'on consacre si peu de ressources à une question qui intéresse, du moins dans une certaine mesure, tout le monde dans ce pays?

**M. Rock:** C'est une bonne question. Est-ce que les ministres provinciaux ont comparu devant votre comité?

**La présidente:** Pas cette fois-ci. Ils ont comparu devant le comité spécial du Sénat.

**M. Rock:** Avez-vous parlé des ressources que consacrent les provinces aux soins palliatifs? On pourrait dire la même chose de l'orthopédie ou de l'obstétrique. Combien d'argent les gouvernements provinciaux consacrent-ils au traitement du diabète? Je ne suis pas prêt à discuter des sommes que consacrent les provinces aux services prioritaires. Je pense toutefois que les ministres provinciaux seraient disposés à le faire.

N'avez-vous pas rencontré les ministres provinciaux lors de la première série d'audiences, en 1995?

**La présidente:** Oui. Cette fois-ci, nous leur avons écrit pour leur demander de nous fournir des renseignements sur les progrès qu'ils ont réalisés. Nous avons, bien entendu, entendu le témoignage d'infirmières et de médecins qui nous ont parlé de ce qui se passait dans leur province respective. Malheureusement, nous avons appris qu'en raison de la compression des dépenses de santé à l'échelle nationale, les soins palliatifs ont été plus durement touchés parce que c'est un domaine nouveau. D'abord, il y a peu de lits consacrés aux soins palliatifs. Quand on les a fermés, le système est tombé en panne dans certains cas. Il n'y avait tout simplement pas de ressources disponibles pour les soins palliatifs.

Nous avons également appris que les soins palliatifs ne sont toujours pas légalement reconnus au Canada. Il y a des médecins qui fournissent des soins palliatifs, mais ces soins ne sont pas



gynaecology. It is not recognized as internal medicine. As a result, since we have few medical schools even engaged in the topic, there are few doctors trained in the field. Obviously, that has led to the significant dilemma of how to deliver care that, quite frankly, no one is trained to provide.

You will hear more on June 6 when we table our report in the Senate.

**Mr. Rock:** Madam Chairman, that is good.

**Senator Corbin:** Is the new medical research institute at arm's-length from you, the minister? Are you in a position, for example, to go beyond suggestions and instruct them to do research in palliative care along the line of the comments that will be in our report? Are you in a position to sort of coach these people, or are they left entirely on their own?

**Mr. Rock:** I believe the legislation that you approved in the Senate was considered by this committee?

**The Chairman:** No, it was considered by the Standing Senate Committee on Social Affairs, Science and Technology, of which we are a subcommittee. However, I sponsored it.

**Mr. Rock:** That legislation creates a governing council of the institutes. The governing council itself will decide what institutes will exist and will appoint advisory councils to each. Thus, the council more or less decides on the direction of the research. I believe the act also contains a provision that the Minister of Health can ask the council to devote its attention to specific areas — I will look at that again, but I think I do have that authority.

I also want to emphasize what I said at the beginning of my remarks. I believe that when the governing council actually sets up the institutes, it will reflect what is an increasingly important area of inquiry, that is, palliative care. I believe it will find its place among the priorities that the council establishes.

**The Chairman:** I should say, Senator Corbin, that I did not feel the same ministerial bounds in sponsoring the legislation. I have been lobbying Dr. Fraser very hard on behalf of an institute for palliative care. There are certain advantages to being a senator rather than a minister, Mr. Minister.

I wish to thank you very much for coming this afternoon and answering our questions in such a positive way.

**Mr. Rock:** Honourable senators, thank you all very much, and thank you for the valuable work you do on these important and difficult issues.

The committee adjourned.

reconnus, comme c'est le cas pour l'obstétrique et la gynécologie. Ils ne sont pas reconnus comme étant une pratique de médecine interne. Donc, comme il y a peu d'écoles de médecine qui donnent des cours là-dessus, il y a très peu de médecins qui se spécialisent dans ce domaine. Nous sommes devant un dilemme important: comment fournir des soins que personne n'est en mesure de dispenser.

Vous aurez plus de précisions à ce sujet le 6 juin, quand nous déposerons notre rapport au Sénat.

**M. Rock:** C'est une bonne chose, madame la présidente.

**Le sénateur Corbin:** Est-ce que le nouvel institut de recherche en santé est indépendant de votre ministère? Êtes-vous en mesure, par exemple, de lui demander de faire des recherches dans le domaine des soins palliatifs, une recommandation que nous comptons formuler dans notre rapport? Êtes-vous en mesure de donner des instructions à ces personnes, ou agissent-elles de façon entièrement autonome?

**M. Rock:** C'est bien votre comité qui a examiné le projet de loi approuvé par le Sénat?

**La présidente:** Non, c'est le comité sénatorial permanent des affaires sociales, des sciences et de la technologie qui l'a examiné. Nous relevons de lui. Toutefois, c'est moi qui ai parrainé le projet de loi.

**M. Rock:** Ce projet de loi crée un conseil d'administration qui sera chargé de créer des instituts et de les doter d'un conseil consultatif. C'est lui qui établira plus ou moins l'orientation à donner à la recherche. Je pense que le projet de loi contient également une disposition qui précise que le ministre de la Santé peut demander au conseil de se pencher sur certaines questions précises — je vais devoir l'examiner à nouveau, mais je pense que j'ai ce pouvoir.

Je tiens également à répéter ce que j'ai dit au début de mon allocution. Quand le conseil d'administration créera les instituts, il mettra l'accent sur un domaine d'activité qui prend de plus en plus d'importance, soit les soins palliatifs. Ils figureront parmi les priorités du conseil.

**La présidente:** Je tiens à dire, sénateur Corbin, que je ne me sentais pas tenue de respecter les mêmes règles ministérielles quand j'ai parrainé le projet de loi. J'ai essayé de convaincre M. Fraser de créer un institut sur les soins palliatifs. Le fait d'être sénateur et non ministre présente certains avantages, monsieur le ministre.

Je tiens à vous remercier d'être venu cet après-midi et d'avoir répondu si clairement à nos questions.

**M. Rock:** Je tiens à vous remercier, honorables sénateurs, de l'excellent travail que vous effectuez dans ce dossier important et difficile.

La séance est levée.



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APPEARING—COMPARAÎT

**Monday, May 15, 2000**

The Honourable Allan Rock, P.C., M.P., Minister of Health.

**Le lundi 15 mai 2000**

L'honorable Allan Rock, c.p., député, ministre de la Santé.

WITNESSES—TÉMOINS

*From the Department of Health Canada:*

Cliff Halliwell, Director General, Applied Research and Analysis Directorate, Information, Analysis and Connectivity Branch;

Barbara Ouellet, Director of Home Care and Pharmaceuticals, Health Care Directorate, Policy and Consultation Branch;

Dr. Christina Mills, Director, Cancer Bureau, Laboratory Centre for Disease Control, Health Protection Branch.

*Du ministère de la Santé:*

Cliff Halliwell, directeur général, Direction de la recherche appliquée et de l'analyse, Direction générale de l'information, de l'analyse et de la connectivité;

Barbara Ouellet, directrice, Direction des soins à domicile et des produits pharmaceutiques, Direction générale des politiques et de la consultation;

Dre Christina Mills, directrice, Bureau du cancer, Laboratoire de lutte contre la maladie, Direction générale de la protection de la santé.

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Second Session  
Thirty-sixth Parliament, 1999-2000

Deuxième session de la  
trente-sixième législature, 1999-2000

## SENATE OF CANADA

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*Standing Senate Committee on Social Affairs,  
Science and Technology*

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*Comité sénatorial permanent des  
Affaires sociales, des sciences et de la technologie*

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*Subcommittee to*

*Sous-comité de*

# Update "Of Life and Death"

# Mise à jour de «De la vie et de la mort»

*Chairman:*  
The Honourable SHARON CARSTAIRS

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*Présidente:*  
L'honorable SHARON CARSTAIRS

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Sous-comité du Comité sénatorial permanent  
des affaires sociales, des sciences et de la technologie  
2<sup>e</sup> session, 36<sup>e</sup> législature, 1999-2000

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- Cameron, Mark**, Coordinator, Care-in-Dying Coalition  
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- Chapman, Marian**, Chair, *Of Life and Death* Update Task Force, Council on Aging of Ottawa-Carleton  
*Of Life and Death*, update, 5:4-9,14-7,19,21
- Chochinov, Harvey Max**, Department of Psychiatry, University of Manitoba  
*Of Life and Death*, update, 4:50-6,60-1,64-7,69-70
- Crelinsten, Gordon L.**, Chair, Committee on Ethics, Canadian Medical Association  
*Of Life and Death*, update, 3:17-9,25,34-7
- Deleury, Edith**, Professor, Université Laval, Barreau du Québec  
*Of Life and Death*, update, 7:12-4,17,27-8,30-1
- Dinsdale, Henry**, Past President, National Council on Ethics in Human Research, Royal College of Physicians and Surgeons of Canada  
*Of Life and Death*, update, 3:31-2,40
- Downie, Jocelyn**, Professor, Health Law Institute, Dalhousie University  
*Of Life and Death*, update, 1:17-24,30-4,36-41,43-6
- Friesen, Henry**, President, Medical Research Council of Canada  
*Of Life and Death*, update, 8:22-5,32-3
- Garrard, Nancy**, Director, Division of Aging and Seniors, Health Promotion and Programs Branch, Health Department  
*Of Life and Death*, update, 4:7-9
- Gaudette, Leslie**, Section Head, Treatment and Palliation Section, Cancer Control Assessment and Surveillance Division, Cancer Bureau, Laboratory Centre for Disease Control, Health Department  
*Of Life and Death*, update, 4:21-2,27
- Gillespie, Brian**, Senior Medical Advisor, Bureau of Pharmaceutical Assessment, Health Department  
*Of Life and Death*, update, 6:13,15
- Gillis, Debra**, Director, Health Programs Support Division, Medical Services Branch, Health Department  
*Of Life and Death*, update, 4:11-3,17-8,26-8
- Halliwell, Cliff**, Director General, Applied Research and Analysis Directorate, Information, Analysis and Connectivity Branch, Health Department  
*Of Life and Death*, update, 4:13-6,20-2; 10:14
- Haughian, Richard**, President, Catholic Health Association of Canada  
*Of Life and Death*, update, 7:10,22,24-5,27
- Bouchard, Carole**, gestionnaire, Bureau des substances contrôlées, Programme des produits thérapeutiques, ministère de la Santé  
*De la vie et de la mort*, mise à jour, 6:5-13,15-6
- Bouvette, Maryse**, infirmière, coordinatrice de l'équipe d'évaluation de la douleur et des symptômes, Programme de soins palliatifs, Service de santé des Sœurs de la Charité d'Ottawa  
*De la vie et de la mort*, mise à jour, 4:30-4,47-8
- Brazeau, Michel**, directeur général, Collège Royal des médecins et chirurgiens  
*De la vie et de la mort*, mise à jour, 3:5-9,23-4,27-30,33-4,36,39-40
- Cameron, Mark**, coordonnateur, Care-in-Dying Coalition  
*De la vie et de la mort*, mise à jour, 6:46-9,60-1
- Chapman, Marian**, présidente, Groupe de travail pour la mise à jour du rapport *De la vie et de la mort*, Conseil sur le vieillissement d'Ottawa-Carleton  
*De la vie et de la mort*, mise à jour, 5:4-9,14-7,19,21
- Chochinov, Harvey Max**, faculté de psychiatrie, The University of Manitoba  
*De la vie et de la mort*, mise à jour, 4:50-6,60-1,64-7,69-70
- Crelinsten, Gordon L.**, président, Comité d'éthique, Association médicale canadienne  
*De la vie et de la mort*, mise à jour, 3:17-9,25,34-7
- Deleury, Edith**, professeure, Université Laval, Barreau du Québec  
*De la vie et de la mort*, mise à jour, 7:12-4,17,27-8,30-1
- Dinsdale, Henry**, président sortant, Conseil national d'éthique en recherche sur l'humain, Collège Royal des médecins et chirurgiens du Canada  
*De la vie et de la mort*, mise à jour, 3:31-2,40
- Downie, Jocelyn**, professeure, Health Law Institute, Dalhousie University  
*De la vie et de la mort*, mise à jour, 1:17-24,30-4,36-41,43-6
- Friesen, Henry**, président, Conseil de recherches médicales du Canada  
*De la vie et de la mort*, mise à jour, 8:22-5,32-3
- Garrard, Nancy**, directrice, Division du vieillissement et des aînés, Direction générale de la promotion et des programmes de la santé, ministère de la Santé  
*De la vie et de la mort*, mise à jour, 4:7-9
- Gaudette, Leslie**, chef de section, Traitement et palliation, Division de la surveillance et de la lutte contre le cancer, Bureau du cancer, Laboratoire de la lutte contre la maladie, Direction générale de la protection de la santé, ministère de la Santé  
*De la vie et de la mort*, mise à jour, 4:21-2,27
- Gillespie, Brian**, conseiller médical principal, Bureau de l'évaluation des produits pharmaceutiques, ministère de la Santé  
*De la vie et de la mort*, mise à jour, 6:13,15
- Gillis, Debra**, directrice, Division du soutien des programmes de santé, Direction générale des services médicaux, ministère de la Santé  
*De la vie et de la mort*, mise à jour, 4:11-3,17-8,26-8
- Halliwell, Cliff**, directeur général, Direction de la recherche appliquée et de l'analyse, Direction générale de l'information, de l'analyse et de la connectivité, ministère de la Santé  
*De la vie et de la mort*, mise à jour, 4:13-6,20-2; 10:14
- Haughian, Richard**, président, Association catholique canadienne de la santé  
*De la vie et de la mort*, mise à jour, 7:10,22,24-5,27



**Hupé, Diane**, Nurse, Vice-President, Palliative Care Program, Sisters of Charity of Ottawa Health Service  
*Of Life and Death*, update, 4:39-46,49-50

**Jarvis, Virginia**, Clinical Research Institute of Montreal  
*Of Life and Death*, update, 9:4-8,15,19-20,22-4,26

**Jeffs, Jacki**, Executive Director, Alliance for Life Ontario  
*Of Life and Death*, update, 6:42-6

**Lank, Heather**, Clerk of the Committee  
*Of Life and Death*, update, 1:9; 3:24

**Lapointe, Bernard**, President, Canadian Palliative Care Association and the Association québécoise de soins palliatifs  
*Of Life and Death*, update, 2:5-10,15-9,25-8

**Latimer, Elizabeth**, Professor, Department of Family Medicine, McMaster University; Presenter, Catholic Health Association of Canada  
*Of Life and Death*, update, 7:6-9,17-20,22-4,26,28-32

**MacDonald, Neil**, Centre for Bioethics, Clinical Research Institute of Montreal  
*Of Life and Death*, update, 8:5-14

**MacLachlan, Richard**, Head, Faculty of Medicine, Dalhousie University, College of Family Physicians of Canada  
*Of Life and Death*, update, 2:11-5,17-8,20-5,27-9

**Mahoney, James**, Alberta Life Foundation  
*Of Life and Death*, update, 6:51-6,58-9

**Martin, Douglas K.**, Research Associate, Joint Centre for Bioethics, University of Toronto  
*Of Life and Death*, update, 5:9-22

**Ménard, Jean-Pierre**, Barreau du Québec  
*Of Life and Death*, update, 7:14-6,18-22,28

**Mills, Christina**, Director, Cancer Bureau, Laboratory Centre for Disease Control, Health Protection Branch, Health Department  
*Of Life and Death*, update, 4:9-11,18-9,22,26

**Mishara, Brian**, Professor, Department of Psychology, Université du Québec à Montréal  
*Of Life and Death*, update, 8:15-9,37-41

**Nield, Sharon**, Manager, Nursing Policy and Regulatory Support, Canadian Nurses Association  
*Of Life and Death*, update, 3:19-23,25,28-9,38

**Noël, Annette**, Vice-President, Board of Directors, Catholic Health Association of Canada  
*Of Life and Death*, update, 7:5-6,27

**Ogden, Russel** (Personal presentation)  
*Of Life and Death*, update, 8:25-9,35-6

**Ouellet, Barbara**, Director of Home Care and Pharmaceuticals, Health Care Directorate, Policy and Consultation Branch, Health Department  
*Of Life and Death*, update, 4:5-7,17-20,23-6,28-9; 10:14,16

**Poston, Jeff**, Executive Director, Canadian Pharmacists Association  
*Of Life and Death*, update, 3:9-12,29,32-3,37,39,41-2

**Rock, Hon. Allan**, Minister of Health  
*Of Life and Death*, update, 10:5-19

**Hupé, Diane**, infirmière, vice-présidente, Programme de soins palliatifs, Service de santé des Sœurs de la Charité d'Ottawa  
*De la vie et de la mort*, mise à jour, 4:39-46,49-50

**Jarvis, Virginia**, Institut de recherches cliniques de Montréal  
*De la vie et de la mort*, mise à jour, 9:4-8,15,19-20,22-4,26

**Jeffs, Jacki**, directrice exécutive, Alliance pour la vie, Ontario  
*De la vie et de la mort*, mise à jour, 6:42-6

**Lank, Heather**, greffière du Comité  
*De la vie et de la mort*, mise à jour, 1:9; 3:24

**Lapointe, Bernard**, président, Association canadienne des soins palliatifs et de l'Association québécoise de soins palliatifs  
*De la vie et de la mort*, mise à jour, 2:5-10,15-9,25-8

**Latimer, Elizabeth**, professeure, département de médecine familiale, McMaster University; témoin, Association catholique canadienne de la santé  
*De la vie et de la mort*, mise à jour, 7:6-9,17-20,22-4,26,28-32

**MacDonald, Neil**, Centre de bioéthique, Institut de recherche clinique de Montréal  
*De la vie et de la mort*, mise à jour, 8:5-14

**MacLachlan, Richard**, directeur, faculté de médecine, Dalhousie University, Collège des médecins de famille du Canada  
*De la vie et de la mort*, mise à jour, 2:11-5,17-8,20-5,27-9

**Mahoney, James**, Alberta Life Foundation  
*De la vie et de la mort*, mise à jour, 6:51-6,58-9

**Martin, Douglas K.**, agrégé de recherche, Centre de bioéthique, University of Toronto  
*De la vie et de la mort*, mise à jour, 5:9-22

**Ménard, Jean-Pierre**, Barreau du Québec  
*De la vie et de la mort*, mise à jour, 7:14-6,18-22,28

**Mills, Christina**, directrice, Bureau du cancer, Laboratoire de la lutte contre la maladie, Direction générale de la protection de la santé, ministère de la Santé  
*De la vie et de la mort*, mise à jour, 4:9-11,18-9,22,26

**Mishara, Brian**, professeur, département de psychologie, Université du Québec à Montréal  
*De la vie et de la mort*, mise à jour, 8:15-9,37-41

**Nield, Sharon**, directrice, Politique des soins infirmiers et soutien à la réglementation, Association des infirmières et infirmiers du Canada  
*De la vie et de la mort*, mise à jour, 3:19-23,25,28-9,38

**Noël, Annette**, vice-présidente, conseil d'administration, Association catholique canadienne de la santé  
*De la vie et de la mort*, mise à jour, 7:5-6,27

**Ogden, Russel** (présentation personnelle)  
*De la vie et de la mort*, mise à jour, 8:25-9,35-6

**Ouellet, Barbara**, directrice, Soins à domicile et produits thérapeutiques, Direction générale des politiques et de la consultation, ministère de la Santé  
*De la vie et de la mort*, mise à jour, 4:5-7,17-20,23-6,28-9; 10:14,16

**Poston, Jeff**, directeur général, Association des pharmaciens du Canada  
*De la vie et de la mort*, mise à jour, 3:9-12,29,32-3,37,39,41-2

**Rock, honorable Allan**, ministre de la santé  
*De la vie et de la mort*, mise à jour, 10:5-19



**Roy, David**, Clinical Research Institute of Montreal  
*Of Life and Death*, update, 9:8-26

**Ryan, Peter**, President, Campaign Life Coalition New Brunswick  
*Of Life and Death*, update, 6:30-3

**Schadenberg, Alex**, Executive Director, Euthanasia Prevention Coalition of Ontario  
*Of Life and Death*, update, 6:33-42,60

**Scher, Hugh**, Chair, Human Rights Committee, Council of Canadians with Disabilities  
*Of Life and Death*, update, 6:16-29

**Schroder, Cori**, Physician, Palliative Care Program, Sisters of Charity of Ottawa Health Service  
*Of Life and Death*, update, 4:34-6,44,46-9

**Sholzberg-Gray, Sharon**, President and Chief Executive Officer, Canadian Healthcare Association  
*Of Life and Death*, update, 3:12-7,25-6,32,35,40-1

**Singer, Peter**, professor, University of Toronto  
*Of Life and Death*, update, 4:56-60,62-4,67-71

**Sneiderman, Barney**, Professor, Faculty of Law, University of Manitoba  
*Of Life and Death*, update, 1:24-9,32-9,42-3,45-50

**Vadboncoeur, Suzanne**, Director, Research and Legislation Division, Barreau du Québec  
*Of Life and Death*, update, 7:10-2,28,32

**Young, James G.**, Chief Coroner, Office of the Chief Coroner of Ontario  
*Of Life and Death*, update, 8:19-22,29-35,40-2

**Roy, David**, Institut de recherches cliniques de Montréal  
*De la vie et de la mort*, mise à jour, 9:8-26

**Ryan, Peter**, président, Coalition Campagne vie du Nouveau-Brunswick  
*De la vie et de la mort*, mise à jour, 6:30-3

**Schadenberg, Alex**, directeur exécutif, Euthanasia Prevention Coalition of Ontario  
*De la vie et de la mort*, mise à jour, 6:33-42,60

**Scher, Hugh**, président, Comité des droits de la personne, Conseil des Canadiens avec déficiences  
*De la vie et de la mort*, mise à jour, 6:16-29

**Schroder, Cori**, médecin, Programme des soins palliatifs, Service de santé des Sœurs de la Charité d'Ottawa  
*De la vie et de la mort*, mise à jour, 4:34-6,44,46-9

**Sholzberg-Gray, Sharon**, présidente-directrice générale, Association canadienne des soins de santé  
*De la vie et de la mort*, mise à jour, 3:12-7,25-6,32,35,40-1

**Singer, Peter**, professeur, University of Toronto  
*De la vie et de la mort*, mise à jour, 4:56-60,62-4,67-71

**Sneiderman, Barney**, professeur, Faculté de droit, The University of Manitoba  
*De la vie et de la mort*, mise à jour, 1: 24-9,32-9,42-3,45-50

**Vadboncoeur, Suzanne**, directrice, Service de recherche et de législation, Barreau du Québec  
*De la vie et de la mort*, mise à jour, 7:10-2,28,32

**Young, James G.**, coroner en chef, Bureau du coroner en chef de l'Ontario  
*De la vie et de la mort*, mise à jour, 8:19-22,29-35,40-2











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